Author:
Starkey, Fenella Anne

Title:
Participatory research with mental health service users : a strategy for empowerment?

Participatory Research With Mental Health Service Users: A strategy for empowerment?

Fenella Anne Starkey

A dissertation submitted to the University of Bristol in accordance with the requirements of the degree of Doctor of Philosophy in the Faculty of Social Sciences and Law

School for Policy Studies
October 2004

Word count: 99,729

Abstract

Literature, including service users' own accounts, confirms that people labelled as 'mentally ill' experience oppression and powerlessness both in their contacts with psychiatric services and more widely in society. There are calls to challenge this oppression by engaging in strategies for empowerment, for example via advocacy and campaigning by the mental health user/survivor movement.

Research has also been identified as a strategy for empowerment for mental health service users. This dissertation proposes participatory research (PR) as a potentially empowering research methodology consisting of a process of investigation, education and action in which participants work jointly with researchers throughout.

This research therefore aims to: explore the nature of oppression and power in the lives of mental health service users in Britain; assess the extent to which participatory research can function as a strategy for empowerment for mental health service users; consider the extent to which PR principles can be adhered to in research with mental health service users; and highlight issues for methodological development arising from the practice of PR.

These aims were explored via a year-long PR project in which the author worked jointly with a group of mental health service users to design and undertake research, and to take action based on its findings. Fieldwork data are analysed in the context of existing theoretical, conceptual and empirical literature on oppression, power, empowerment and PR.

It is concluded that PR can facilitate processes of individual and group empowerment for mental health service users, and may therefore be a first step towards the longer-term goal of achieving empowerment in the liberational sense of changing oppressive social structures. This latter goal is more likely to be achieved by combining research with other strategies for empowerment such as collective action and campaigning, and by joining together with other oppressed groups with common interests, such as the disability movement.

Acknowledgements

There are many people whom I would like to thank for supporting me during these doctoral studies.

Most importantly, thank you to my co-researchers. I very much enjoyed getting to know you all and spending time with you during this project. Working with you was a hugely rewarding experience, from which I learned a great deal.

Many thanks also to the project worker, for your invaluable support and sound advice throughout this project, and to your employing organisation for allowing me to take you away from a very busy service once a week for a year and for supporting this research.

Thank you to Randall Smith, my supervisor. I have greatly appreciated your guidance, support and wisdom throughout my studies, and know that these have been invaluable in helping me to reach this point.

Sincere thanks also go to my employers and colleagues, for funding, advice and support to enable me to carry out these studies over several years. Particularly special thanks go to Ruth Northway and Liz Frost for commenting on a draft version of this dissertation.

Finally, heartfelt and loving thanks to my family and friends for their patience and helpful words of encouragement in supporting me to complete my studies.

This dissertation is dedicated to my much-loved nan and granddad, who both passed on before I could complete this work.

Author's declaration

I declare that the work in this dissertation was carried out in accordance with the Regulations of the University of Bristol. The work is original except where indicated by special reference in the text and no part of the dissertation has been submitted for any other degree.

Any views expressed in the dissertation are those of the author and in no way represent those of the University of Bristol.

The dissertation has not been presented to any other University for examination either in the United Kingdom or overseas.

SIGNED: .....

DATE: 8th October 2004

Table of contents

List of figures

List of tables

List of appendices

List of abbreviations

A&E	Accident and Emergency Department (of hospital)
APA	American Psychiatric Association
ASW	Approved Social Worker
BPS	British Psychological Society
BSA	British Sociological Association
CINAHL	Cumulative Index to Nursing and Allied Health
CMS	Care Management System (Social Services)
CPA	Care Planning Approach (National Health Service)
CPN	Community Psychiatric Nurse
CPPIH	Commission for Patient and Public Involvement in Health
DSM	Diagnostic and Statistical Manual of Mental Disorders
ECT	Electro-convulsive Therapy
ER	Emancipatory Research
Folk.us	The Forum for Collaboration With Users in Research
GP	General Practitioner
HIV	Human Immuno-Deficiency Virus
ICD	International Classification of Diseases, Injuries, and Causes of Death
LETS	Local Exchange Trading Scheme
NIMHE	National Institute for Mental Health in England
NHS	National Health Service
OCD	'Obsessive Compulsive Disorder'
ODPM	Office of the Deputy Prime Minister
PAG	Project Advisory Group
PAR	Participatory Action Research
PCS Model	Personal, Cultural and Social Model of Oppression
PR	Participatory Research
PRA	Participatory Rural Appraisal
RRA	Rapid Rural Appraisal
SCIE	Social Care Institute for Excellence
SCPR	Social and Community Planning Research
UK	United Kingdom
US	United States (of America)
USA	United States of America
WHO	World Health Organisation

Introduction

Aims of the research

I embarked upon this research due to a personal concern about people's experiences of powerlessness and oppression within the mental health system, which led me to consider undertaking research into advocacy as a potential strategy to counter such experiences. My exploration of appropriate research methodologies encouraged me to consider the use of a participatory research (PR) methodology, both to counter oppression within the research process itself and possibly to act as a broader strategy for empowerment for mental health service users.

As I felt that the PR process might function in a similar way to advocacy, in terms of empowering people to voice their experiences and concerns and take action, it was clear that it would be difficult to separate out the effects of the PR process from advocacy processes. This initial exploration therefore refocused my research aims, from considering the use of advocacy as a means of empowerment for mental health service users to exploring whether PR methodology could serve a similar purpose.

This research therefore aims to: explore the nature of oppression and power in the lives of mental health service users in Britain; assess the extent to which PR can function as a strategy for empowerment for mental health service users; consider the extent to which PR principles can be adhered to in research with mental health service users; and highlight issues for methodological development arising from the practice of PR.

Terminology

As can be seen above, I am using the term 'mental health service user' to refer to people with experience of mental distress. The issue of mental health terminology is problematic, with various terms used by different interest groups (Beresford and Wilson, 2002).

Some people in the mental health user/survivor movement use '(psychiatric) survivor' to refer to themselves "in terms of their oppression by the... psychiatric system" (Beresford and Wilson, 2002:543). However, it is acknowledged that this is not how many people identify themselves, and is also increasingly problematic as more people are 'treated' in community services and the concept of 'surviving' the inpatient system becomes less relevant to some people.

However, the term 'mental health service user' also raises issues in that it suggests "a kind of false neutrality" (Barnes et al, 1999:7) in terms of voluntary and unproblematic service use, and narrowly defines people in relation to service use (Beresford, 2001a).

Nonetheless, 'service user' is an umbrella term that is commonly used both in mental health and in other health and social care fields, and is one to which people involved in user/survivor organisations do not tend to object. I have therefore used 'mental health service user' in this dissertation as a generic term to refer to people experiencing mental distress.

Literature about organisations of people experiencing mental distress in Britain tends to refer to 'the user/survivor movement' to encompass both of the above concepts, and this terminology has therefore been retained in this dissertation.

In the light of substantial criticisms of the medical model of 'mental illness' (explored in Chapter One), I avoid the use of the terms 'mentally ill' or 'people with mental illness' unless I am explicitly referring to literature or models which do refer to people in this way. Instead, I use the term 'people with experience of mental distress', to illustrate my rejection of this medical model in favour of social models which I consider to make an important contribution to understanding people's experiences of distress (as discussed in Chapter One).

It is also important at the outset to highlight terminology used in relation to the people with whom I undertook fieldwork. In line with PR's aim of moving away from the traditional 'researcher'/'researched' dichotomy to a situation where people work together as equals, the group of mental health service users with whom I

worked are referred to as 'co-researchers'. I refer to myself sometimes as 'the researcher', as shorthand for 'the external researcher', namely the person that initiated the project and approached a group to become involved in research. However, this is not used to suggest any superiority in position in relation to my co-researchers. I also refer to myself sometimes as 'the research student', to reflect my status both as a university student and as a co-learner in the research process.

For these reasons, I purposefully refer to the PR work that we undertook together as 'our' research and not 'my' research. This draws a distinction between 'our' PR project, and 'my' research for 'my' dissertation, which has involved original work in the form of reviewing and critical analysis of theoretical, conceptual and empirical literature, fieldwork analysis and synthesis of the two to draw conclusions in relation to my research aims.

Structure of study

A review of literature was undertaken on research methodology, the nature of mental distress, oppression, power, mental health service users as an oppressed group, and empowerment. This review continued throughout the research, and involved searches of bibliographic databases[1], university library catalogues, and 'grey' literature originating from user/survivor organisations. The review primarily focused upon British literature, as this research was concerned with the situation of mental health service users and systems in Britain, although key American texts were also included where appropriate. Much of the early PR literature was American, and this is therefore included.

This literature review led to the identification of an appropriate research methodology for working with oppressed groups, namely PR, and exploration of the concepts of oppression, power and empowerment, which are central to the theory and practice of PR. Although the review highlighted models of oppression, power and empowerment which were felt to be most relevant to working with mental health service users as an oppressed group, the research aimed to explore the way that

[1] Databases searched included the Social Science Citation Index, Medline and CINAHL.

mental health service users themselves experienced processes of oppression, power and empowerment.

My research aims were explored via a PR project in which I worked jointly with a group of people using a community-based drop-in centre for people with long-term experience of mental distress. My co-researchers and I designed and undertook research together (primarily group interviews with local health and social care professionals), analysed research findings and took action based on these findings.

This work with co-researchers took place over the course of a year, yet my doctoral studies have spanned eight years on a part-time basis. This highlights the distinction between research and analysis carried out jointly with co-researchers, and additional studies undertaken to demonstrate originality of work on my part. This work included undertaking a qualitative, process-focused evaluation of individual and group empowerment processes occurring during our PR project, and critically analysing our fieldwork findings in the context of theoretical and conceptual frameworks on oppression, power and empowerment.

PR aims to redistribute power in the research process and to break down the traditional barrier between the 'researcher' and the 'researched'. Explicitly locating myself within the research process contributes to this aim, and for this reason I write in the first not third person in this dissertation.

Structure of dissertation

This dissertation is structured such that relevant theoretical, conceptual and empirical literature is reviewed to contextualise the fieldwork and highlight theories that might be relevant to the research aims. Fieldwork data are presented thematically (in line with the research aims), and are critically analysed in the context of literature reviewed to assess the robustness of certain theories in the light of our research.

The first part of the dissertation is therefore concerned with literature reviewed. The contested nature of mental distress is explored in Chapter One in order to highlight the dominant yet problematic status of the medical model of 'mental illness', and its oppressive consequences. Chapter Two clarifies the meanings of oppression, power and professional power, and outlines ways in which oppression and power operate, while Chapter Three analyses models of empowerment, recovery, involvement and participation, key concepts in relation to the research aims.

Chapter Four then explores empirical evidence on the nature of oppression and power experienced by mental health service users in Britain. This chapter argues that mental health service users can be identified as an oppressed group, which raises the issue of how this oppression might be challenged. Strategies for empowerment adopted in Britain by mental health service users, and the corresponding policy context, are therefore also highlighted in Chapter Four.

Having established that mental health service users are an oppressed group and that research might play a role in countering such oppression, Chapter Five outlines the research methodology, including the rationale for selecting PR as a potentially empowering and emancipatory research methodology. Chapter Six describes in detail the complex research design for this doctoral work, including the way in which this design links to the chosen methodology, ethical considerations, and the research and analysis methods used to address the research aims.

The third part of the dissertation critically analyses data from our PR project in the light of theoretical and conceptual frameworks reviewed earlier, presented according to themes emerging from the research aims. As the fieldwork was based on Maguire's (1987) framework for conducting PR, it is presented according to the phases of this framework. Phases One, Two and Three (organising the research, exploring experiences and posing problems) are presented in Chapter Seven, Phase Four (researching reality and analysing data) in Chapter Eight and Phase Five (taking action) in Chapter Nine. Chapter Ten describes a sixth phase, based on Northway's (1998) adaptation of Maguire's framework, namely ending the research.

The discussion presented in Chapter Eleven critically reflects upon the fieldwork data in the light of literature analysed earlier in the dissertation, in relation to the four research aims. Conclusions are then drawn in Chapter Twelve with regard to the original contributions to knowledge advancement made by this doctoral work, and some research, policy and practice implications of its findings.

Chapter One: Conceptualising mental distress

Introduction

This chapter explores the contested issue of conceptualising mental distress, drawing upon sociological, professional and service user literature. The medical model of 'mental illness' is critically examined and shown to be flawed on a number of significant counts. Damaging consequences of this medical model are also identified.

Social approaches to conceptualising mental distress are explored to highlight the complex links between social conditions and processes and mental distress. Social factors resulting from structural inequalities are shown to play a role in experiences of mental distress in different ways: in the increased likelihood of members of oppressed groups developing mental distress due to the social, political and cultural context in which they live; in the social construction of categories of 'mental illness' which are applied to this distress by society's dominant groups; and in the poorer treatment of people from oppressed groups once they receive a label of 'mental illness' both by psychiatric services and by society. Such social perspectives have been drawn upon by mental health service user/survivor movements in Britain and elsewhere to develop their own social models of mental distress.

The medical model of 'mental illness'

The medical model of 'mental illness' upon which psychiatry is based can be defined thus:

> 'Mental' disorders such as schizophrenia or severe depression are deemed to arise from the presence of genetic or biological factors, from identifiable biochemical processes, and to be treatable by pharmacological intervention once recognized and correctly diagnosed. (Braye and Preston-Shoot, 1995:51)

This medical model considers experiences of mental distress to be universal and cross-cultural 'symptoms' of an underlying 'illness' (Penfold and Walker, 1983), analogous to medicine's approach to physical illness (Corrigan and Penn; 1997). The medical model is therefore based upon certain assumptions, including that: these

'symptoms' cluster together into recognisable patterns, which can be used to diagnose 'mental illness'; such diagnoses can be made reliably, and have a strong validity; and medical expertise is required to identify and 'treat' the causal processes underlying such clusters of 'symptoms' (Sheldon, 1984). This 'treatment' of 'mental illness' involves physical interventions such as psychotropic drugs and electro-convulsive therapy (ECT), which aim to alter biochemical reactions in the brain and thereby relieve psychological 'symptoms' (Comer, 2001).

This model continues to dominate mental health research and 'treatment' (Beresford, 2002a; Pilgrim, 2002), thereby legitimising the exercise of power by mental health professionals and their institutions in the lives of people experiencing mental distress.

Nonetheless, Busfield (1996a:146) notes a tendency by some authors to oversimplify the medical model of 'mental illness' and its primary emphasis on biological causation, highlighting other influences on psychiatry such as psychoanalysis. A biopsychosocial model of 'mental disorder', whereby biological, psychological and social factors are all seen to contribute to the development of mental distress, has indeed been advocated by some psychiatrists, for example Clare (1980). However, critics of this approach argue that it allows its advocates "to smuggle in the idea of genetic/biological influences as being primary, under the guise of eclecticism" (Johnstone, 2000:250). This can be seen in Pilgrim's (2002) observation that one of the biopsychosocial model's promising features is that "in day-to-day clinical practice the model also creates the option of seamlessly combining physical and psychological treatments, without undermining the doctor's diagnostic authority" (p.589).

Similarly, the 'stress-vulnerability' model of 'mental illness', highlighted as "the recent orthodoxy in psychiatry" (Rogers and Pilgrim, 2003:175), identifies a genetic vulnerability to 'mental illness', which will only lead to the development of mental distress when 'triggered' by social stressors. Different degrees of vulnerability will therefore require different levels of environmental stress to trigger mental distress. In this way, the 'stress-vulnerability' model ensures that "genetic assertions about causality are logically incontrovertible" (Rogers and Pilgrim, 2003:175), as it can be

used to explain why only some members of certain populations become mentally distressed when all are exposed to the same social stressors (for example poverty). Equally insidious is the way in which the 'stress-vulnerability' model acknowledges social problems, but only as 'triggers' for some underlying biologically-based 'mental illness' (Johnstone, 2000).

The origins of a medical approach to mental distress

To explain the dominance of the medical model of 'mental illness', it is important to briefly consider the history of its development and that of psychiatry. The 'traditional' account of psychiatry highlights medicine's claims in the nineteenth century to have established some physical basis for 'lunacy' in brain function, its increasing knowledge of genetic and biochemical influences on the development of such 'mental illness' and accompanying psychopharmaceutical developments, and its expansion into the realms of less 'severe' 'mental illnesses' (the 'neuroses') via the development of psychotherapeutic theory and practice (Penfold and Walker, 1983).

However, it can be argued that such an account is misleading, both in presenting the development of science as a logical process and in focusing upon physicians' humanitarian rather than entrepreneurial motives. The history of psychiatry's development can instead be understood as the development of approaches to controlling 'difficult' people, with psychiatry's growth as a profession resulting from medicine's authority, status and political power and its members' corresponding ability to assert both moral and 'expert' authority in the care and 'treatment' of the 'mentally ill' (Penfold and Walker, 1983; Scull, 1979)[2]. This gave psychiatry 'carte blanche' to develop theories and treatments based on their (arguably inappropriate) medical interpretation of human experiences (Scull, 1979):

> Historically, had the medical profession not established its dominance in State-delegated powers to manage madness, then we would now be faced with a different way of understanding and organising mental health work. (Rogers and Pilgrim, 2003:192)

However, the validity and legitimacy of the medical model of 'mental illness' has been challenged on a number of levels, explored in the following sections.

---

[2] Further detail on the historical development of psychiatry and psychiatric institutions can be found in Penfold and Walker (1983) and Scull (1979). This detail is not included here as these historical accounts are not a central focus of this dissertation.

Claims for a genetic or biological basis for mental distress

Only very few forms of mental distress have been found to result from some underlying physical problem, for example dementia and Huntington's disease (Rose S., 2001). In all other cases psychiatry's claims for a biological or genetic basis for mental distress remain unproven (Kinderman and Cooke, 2000).

With regard to claims of genetic inheritance, research upon which such declarations are based has been proven to be methodologically flawed and its conclusions crude and over-emphasised (Johnstone, 2000). For example, research into the prevalence of the diagnosis of 'schizophrenia' amongst identical twins, and amongst adopted children with biological parents with this diagnosis, has claimed that "the closer the biological relationship, the greater the risk of a relative also having the diagnosis" (Kinderman and Cooke, 2000:24). Such research has been used by psychiatry as proof of a genetic basis for 'schizophrenia'. However, in addition to the serious methodological flaws that have subsequently been identified in such studies (Johnstone, 2000)[3], this higher incidence could equally be attributable to social or environmental factors (Kinderman and Cooke, 2000).

More recent research comparing adopted children with biological mothers with a diagnosis of 'schizophrenia' to those whose biological mothers did not have such a diagnosis found a higher prevalence of children with diagnoses of 'schizophrenia' in the former group but only where their adoptive family had been rated as 'disturbed' (Kinderman and Cooke, 2000). This finding suggests that it may be the quality of family relationships (a social factor) that plays a role in the development of mental distress, rather than inherited genes (Johnstone, 2000).

Rose (S., 2001) advances a powerful argument against psychiatry's "neurogenetic determinism" (p.s3), noting that it is not possible to identify one fixed 'gene for' any phenomenon as even something as apparently straightforward as eye colour involves a range of fluid biochemical processes and related genes. Furthermore, the idea that it is possible to identify a genetic basis for eye colour or 'schizophrenia' is predicated

[3] For example, the use of very broad definitions of 'schizophrenia' and post-mortem diagnosis (Johnstone, 2000).

upon the assumption that the phenotype under consideration exists and can be identified in the population. While this endeavour may be possible for eye colour, psychiatry's diagnostic categories cannot be viewed as such unitary phenotypes, as will be shown in the next section. Rose (S., 2001) therefore observes that "claims that there are gene markers, or even genes, that are predictive of schizophrenia or depression have been made and withdrawn so many times now as to encourage only healthy scepticism" (p.s5).

Theories have also been advanced that biochemical imbalances in the brain, for example in the production of neurotransmitters such as dopamine or serotonin, are responsible for causing mental distress (Kinderman and Cooke, 2000). However, such claims exemplify the circular arguments often put forward by proponents of the medical model (Sheldon, 1984). It is entirely possible that the mental distress being experienced causes biochemical changes in the body, rather than the reverse as psychiatrists claim. The fact that many people on whom such research is undertaken may be taking powerful medication which affects their biochemistry is also not adequately addressed (Johnstone, 2000). Similarly, claims that abnormalities in brain structure may be a cause of mental distress ignore the possibility that "life experiences, psychological trauma, severe distress, and psychotic experiences may themselves leave physical traces on the brain" (Kinderman and Cooke, 2000:26).

A further issue with research claiming to identify physical causes for mental distress is that it tends to be based upon diagnostic categories of 'mental illness' such as 'schizophrenia'. If these diagnoses themselves are not valid or reliable (as demonstrated below), then research based upon these flawed constructs is unlikely to be meaningful.

The medical model's diagnostic and classification system

The medical model of 'mental illness' is based upon a system of diagnosis and classification of 'disorders', which mirrors that used in general medicine and as such gives it status and credibility (Boyle, 1999). However, both the validity and reliability of psychiatry's diagnostic approach have been shown to be questionable (e.g. Kutchins and Kirk, 1997; Sheldon, 1984).

The sixth edition of the World Health Organisation (WHO)'s International Classification of Diseases, Injuries, and Causes of Death (ICD) published in 1948 included a section on 'mental disorders' (Comer, 2001). However, this section was not widely accepted by psychiatry, and the American Psychiatric Association (APA) therefore produced its own Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1952. Since this time, psychiatrists have struggled to agreed on categories and corresponding symptoms to include in such classification systems, and have produced numerous revisions[4].

The current edition of the American manual, the DSM-IV[5], functions as the definitive 'guide' to medical definitions of 'mental illness' (Comer, 2001). The DSM lists hundreds of 'mental disorders' with criteria for their diagnosis and 'key clinical features'. However, Kutchins and Kirk (1997) have undertaken detailed analysis of the APA's development of the DSM to demonstrate its poor validity and reliability, and its political not scientific nature.

Kutchins and Kirk identify 'mental illness' as a construct, namely "an abstract idea held together by agreements" (p.28). They suggest that the DSM has sought to prove the validity of the 'mental disorders' listed within by simply providing checklists of 'symptoms' for those 'disorders' without providing a clear definition of the construct of 'mental disorder'. The definition of 'mental disorder' offered in the third edition of DSM (DSM-III)[6] is heavily criticised by Kutchins and Kirk for identifying 'mental disorder' as "a manifestation of a behavioral, psychological, or biological dysfunction" (p.31) without defining the meaning of 'dysfunction'. They argue that as the purpose or function of many of our mental mechanisms is unknown, attempting to define their 'dysfunction' is not possible.

---

[4] The WHO produced a revised classification system in 1965, while in 1968 the APA produced DSM-II, similar to the WHO system and which included a glossary of definitions for the UK. Nonetheless, there was still little consensus on the categories included. The DSM-II and the British 'Glossary of Mental Disorders' had some detail on 'symptoms' and behaviours, but they did not include the same 'symptoms' for particular 'disorders', leading to wide variation in diagnostic practice (Davison and Neale, 2001). The ICD underwent more revisions, with ICD-10 being produced in 1992 after the implementation of field trials intended to refine the diagnostic categories (WHO, 1992). Further revisions of the DSM also took place in 1980, 1987 and 1994 (Davison and Neale, 2001).

[5] DSM-IV was first published in 1994 and revised in 2000.

[6] Published in 1980.

Similarly, Kutchins and Kirk criticise the DSM for including lists of criteria for diagnosis of 'mental disorders'[7] which encompass many 'everyday' human reactions and experiences (such as anxiety, insomnia and depressed mood), yet failing to consider the biographical and social context of people's experiences to establish when such reactions "are the result of a mental disorder and when they are the result of the vicissitudes of life"(p.252).

An important argument advanced by Boyle (1999) to challenge the construct validity of psychiatry's diagnostic approach is that the diagnostic process used in general medicine has not been applied to psychiatry in the same way. She argues that diagnosis in general medicine involves discovering a new example of patterns of 'symptoms' that have previously been identified by researchers, and then inferring the same diagnostic label or concept from those patterns. Two assumptions underpin this diagnostic process: firstly, that a relationship has already been discovered between the phenomena and therefore the concept being used as a diagnostic label has been justifiably inferred; and secondly, that there are underlying biological or psychological processes that 'hold together' the pattern or cluster of phenomena already identified.

Boyle argues that the validity of both these assumptions has been questioned. She uses the example of 'schizophrenia', arguing that "there is no evidence whatsoever that the original introduction of the concept of schizophrenia was accompanied by the observation of a meaningful relationship amongst the many behaviours and experiences from which the concept was inferred" (p.80). Indeed, Kinderman and Cooke's (2000:17) review of research using statistical techniques to test the validity of diagnostic categories found no evidence of a meaningful 'clustering' of supposed 'symptoms' of 'disorders' such as 'schizophrenia'.

As a result, Boyle argues that research findings based on existing psychiatric diagnostic categories will be unreliable. Similarly, she suggests that the APA's attempt to define categories of 'mental illness' in DSM-III more clearly by establishing committees to work on lists of criteria for each 'disorder' is a "back-to-

[7] These lists of criteria were incorporated from DSM-III onwards.

front version of science", as "the crucial first stage of concept formation, without which the idea of diagnosis is meaningless, has not been carried out" (p.82).

It has been suggested that "the diagnostic emphasis under DSM is one of neutrality about aetiology" (Rogers and Pilgrim, 2003:178). Sheldon (1984) argues that psychiatry's reliance on interpreting behaviour in order to make diagnoses is inadequate, as he demonstrates in this example:

> ... the existence of the schizophrenia is inferred from the symptom, which is the only evidence in existence. Therefore, Mr Smith's paranoid behaviour is said to be the result of his schizophrenia, which we know he has because of his paranoid behaviour, which is a primary symptom of schizophrenia... (p.86)

Boyle argues that such conceptual problems also result in "unacceptably low" (p.81) rates of diagnostic reliability, a critical element of psychiatry's claims to have a valid system for diagnosing 'mental illness' (Kutchins and Kirk, 1997). There was strong evidence during the period when DSM's first two versions were in use (1950s to 1970s) of varying diagnostic standards amongst psychiatrists, and of disagreements between psychiatrists trying to agree on a diagnosis for someone (Gelder et al, 1983; Johnstone, 2000). Kutchins and Kirk argue that although DSM-III's authors claim high reliability for its diagnostic categories compared to earlier versions, research evidence does not substantiate this claim. They report findings of a major study of DSM-III's reliability published in 1992[8], which entailed giving detailed training to mental health clinicians in how to make accurate DSM diagnoses. When these clinicians were then asked to make diagnoses in pairs, they disagreed so frequently that measures of reliability obtained were no better than those obtained in research in the 1950s and 1960s using earlier versions of the DSM, and in some cases were worse.

These powerful arguments challenge the whole basis of the medical model, namely that clearly defined 'illnesses' can be systematically 'diagnosed' and correspondingly 'treated'. If categories of 'mental illness' are not valid, it is hardly surprising that clinicians are unable to reliably 'diagnose' such 'disorders'. This renders the medical model's conceptualisation of 'mental illness' potentially untenable.

---

[8] This study was carried out in the USA and Germany.

Strong arguments have also been advanced to demonstrate the political and social nature of psychiatry's definition and application of categories of 'mental illness' (Campbell and Heginbotham, 1991; Lindow, 1995). The 'anti-psychiatry' writers of the 1960s and 1970s (e.g. Laing, 1967; Scheff, 1996; Szasz, 1973) focus upon psychiatry's social control role in defining certain members of society as 'mentally ill' (see p.18). Kutchins and Kirk (1997) argue that revisions of categories of 'mental disorder', made as new editions of the DSM were produced, largely resulted from power struggles and political compromises between vested interests (such as psychiatrists, pharmaceutical companies and researchers) rather than from advances in science and empirical evidence[9]. For example, homosexuality is widely cited as a category of 'mental disorder' which was only removed from the DSM in the 1980s, after extensive lobbying from gay rights activists and debate amongst practitioners about the acceptability of labelling a sexual orientation as 'abnormal' (Manning, 2000).

Hence it can be seen that the medical model of 'mental illness' is flawed, both in its claims for a genetic or biological basis, and in the validity and reliability of its diagnostic categories. Nonetheless, it continues to be the dominant explanatory model used by mental health services, and as such affects the lives of many thousands of people. Some of the damaging consequences of the use of this model are highlighted in the following section.

Damaging implications of use of the medical model

Individualising and pathologising experiences

Rogers and Pilgrim (2003) identify biodeterminism and psychoanalysis as the two dominant psychiatric models of the twentieth century, and view both of these as highly individualistic in their assumptions and approaches. Psychiatry can be seen to present 'mental illness' as "morally neutral" (Sayce, 2000:87), due entirely to an individual's physiological and psychological make-up rather than to any oppressive

[9] The way in which psychiatric diagnoses are socially constructed and reflect structural inequalities, power imbalances and corresponding oppression in society, such as sexism and racism, is explored later in this chapter in the context of social constructionist approaches to mental distress.

characteristics of society (Busfield, 2000). In this way, psychiatry succeeds in individualising and internalising problems which may be due to structural inequalities (Beresford, 2002a; Breggin, 1993), thus masking their political context (Penfold and Walker, 1983:25).

This medical approach to interpreting people's distress as merely 'symptoms' of an 'illness' also serves to deny the validity of those feelings (Johnstone, 2000). Beresford (2002a) notes the way in which the medical model "is based on a deficit model, which presumes the pathology and inadequacy of the 'mentally ill' and which conceptualises their thoughts, emotions, perceptions and behaviours as wrong and defective" (p.582), rather than as natural reactions to traumatic experiences, for example (Lindow, 1995). Furthermore, it can be argued that psychiatry is increasingly medicalising and pathologising "more and more behaviors that are less and less abnormal" (Kutchins and Kirk, 1997:240), as can be seen in the significant increase in the number of young people who are struggling or being disruptive at school being labelled with DSM-defined 'disorders' such as 'attention-deficit/hyperactivity disorder', and pharmacologically 'treated' accordingly (Busfield, 1996a).

Use of physical 'treatments'

Another damaging consequence of the dominance of the medical model of 'mental illness' in conceptualising mental distress is the pre-eminence given by psychiatry to physical 'treatments' such as psychotropic drugs and ECT (Breggin, 1993; Rogers and Pilgrim, 2003), which have severe and extremely distressing side-effects (Gomm, 1996)[10]. Increasing use of 'treatments' which aim to alter people's biochemistry is all the more concerning in light of the fact that "most biological interventions in common use... have not been derived from knowledge of what causes a given disorder" (Davison and Neale, 2001:24).

As highlighted above, these physical 'treatments' aim to suppress people's 'symptoms', i.e. their experiences and behaviours, potentially locking people into cycles of unhelpful 'treatment' which do not address the underlying reasons for

[10] The side-effects of physical psychiatric treatments are discussed in more detail in Chapter Four of this dissertation.

people's experiences (Busfield, 1996b; Johnstone, 2000). Use of physical 'treatments' to reinforce psychiatry's role in controlling disruptive conduct for society has also been highlighted, as these can be administered against someone's will (Pilgrim and Rogers, 1993).

This widespread reliance upon physical 'treatments' also means that people are less likely to be offered 'talking treatments' such as psychotherapy (Kinderman and Cooke, 2000), which research consistently shows are preferred by people experiencing mental distress (Pilgrim and Rogers, 1993)[11].

Oppression of people labelled 'mentally ill'

The dangers of psychiatry's unsubstantiated claims about a genetic or biological basis for mental distress are apparent. Such emphasis on identifying genetic predispositions to 'mental illness' may lead to attempts to define people as 'mentally ill' from birth, with the attending oppression and disadvantage (Campbell, 1999a; Jones et al, 2001).

Such biogenetic explanations "also help fuel beliefs about the *permanent* and *irreversible* nature of 'mental illnesses'" (Beresford and Wilson, 2002:542[12]), thereby making recovery far more difficult for people experiencing mental distress.

Classifying people may also have negative consequences due to the oppression experienced by people labelled by psychiatry as 'mentally ill' (Comer, 2001; Cooper and Cooper, 1988) and the damaging impact upon their social status and identity (Scheff, 1966)[13].

Against this backdrop of the damaging and poorly substantiated medical approach to diagnosing and 'treating' 'mental illness', alternative social explanations have been offered. These attempt to understand mental distress in the context of people's past

---

[11] It should be noted, however, that such 'talking treatments' have also been criticised as potentially abusive and oppressive (Chesler, 1974; Davis et al, 1985; Ussher, 1991). Rogers and Pilgrim (2003) therefore caution against adopting an oversimplified view of physical 'treatments' as 'bad' and 'talking treatments' as 'good', in that the latter also involves the exercise of professional power over people (p.224), and both still take an individualistic and pathology-based approach to 'treatment'.

[12] Original emphasis.

[13] Ways in which people labelled as 'mentally ill' experience oppression are explored in greater depth in Chapter Four of this dissertation.

and present experiences and the social, cultural and political conditions in which they live.

Social models of mental distress

Research shows that reported rates of mental distress are higher amongst oppressed groups, for example women (Chesler, 1974; Davis et al, 1985), Black and minority ethnic groups (Fernando, 1995; Melzer et al, 2002), and working-class people (Busfield, 1996a; Melzer et al, 2002). A range of social approaches to conceptualising this distress has been proposed to explain these powerful findings and challenge the predominance of biological explanations. Social models of mental distress have been developed since the 1960s by social scientists, inspired by the growth of civil rights movements such as feminism and by growing awareness of the oppressive nature of capitalist societies' structural inequalities. Such models include labelling theory, social constructionism, and social production approaches to understanding distress. These are explored in turn in the following sections.

'Anti-psychiatry' and the labelling perspective

In the 1960s and 1970s, a group of 'anti-psychiatry' theorists (including both psychiatrists and social scientists) emerged to highlight psychiatry's role in regulating human behaviour for society by 'diagnosing' 'mental illness' (Busfield, 1996a).

Szasz (1973), an American psychiatrist, argues that 'mental illness' is a myth that masks psychiatry's social control role. He does not deny the existence of "the social and psychological occurrence to which this label is attached" (p.21), but instead defines these as "problems in living" (p.13). Szasz challenges the analogy of 'mental illness' and physical illness, arguing that behaviour labelled as 'mental illness' merely represents a deviation from social, ethical and legal norms, and as such is not appropriately 'treated' via medical interventions (p.17).

Similarly, the British psychiatrist Laing (1967:86) views 'schizophrenia' not as an 'illness' but as a label applied to people under particular social circumstances. Laing

advocates understanding people's experiences and behaviour in context rather than viewing such experiences as invalid and ignoring them. Similar to Szasz, he suggests that "the experience and behaviour that gets labelled schizophrenic is *a special strategy that a person invents in order to live in an unlivable situation*" (p.95[14]), and therefore argues that "the social system, not single individuals extrapolated from it, must be the object of study" (p.95).

Goffman (1961, 1990[15]), whose sociological work comes from a symbolic interactionist perspective, focuses upon the stigmatisation of people in mental distress resulting from their interactions with members of society in relation to acceptable social norms. Goffman defines stigma as "an attribute that is deeply discrediting" (1990:13), which functions to turn people away from those who possess it due to their "undesired differentness" (p.15). He argues that 'normal' people view stigmatised people as 'less than human', and that this justifies discrimination towards them and impacts upon their 'life chances'. Goffman (1961:309-310) also argues that the impact of psychiatric institutionalisation upon people, including their experiences of 'disculturation'[16] and 'role-dispossession', is compounded by the stigmatisation they experience outside psychiatric hospital.

Scheff (1966, 1996[17]) also drew upon symbolic interactionism to propose labelling theory, identified as the dominant sociological paradigm for explaining 'mental illness' in the 1960s and 1970s (Turner, 1987). Scheff (1966) criticises psychiatry's approach to 'mental illness' for ignoring social processes, and instead proposes a social system model of mental disorder "in which psychiatric symptoms are considered to be labeled violations of social norms" (p.25).

Scheff's (1966:33) key concepts include 'rule-breaking', identified as "violations of social norms", and 'deviance', defined as "particular acts which have been publicly and officially labeled as norm violations". Scheff identifies "most psychiatric symptoms as instances of residual rule-breaking or residual deviance". He therefore

---

[14] Original emphasis.
[15] First published in 1963.
[16] Disculturation is defined as "an 'untraining' which renders him *(sic)* temporarily incapable of managing certain features of daily life on the outside" (Goffman, 1961: 23).
[17] First published in 1970 as 'Schizophrenia as Ideology', in the Schizophrenia Bulletin.

argues that 'mental illness' is a 'residual' category of deviance, used to explain behaviour that cannot be accounted for in any other way, for example due to eccentricity or drunkenness. Scheff (1996) views societal reaction to such behaviour as playing a crucial role in the process of creating 'mental illness', highlighting the way in which this reaction varies according to social contexts and the power and status of the person at risk of being labelled.

Scheff therefore views 'mental illness' as a social role and argues that once labelled as 'mentally ill', people are rewarded by psychiatry for fulfilling this social role and are punished (for example via discrimination in the workplace and social situations) if they try to return to their former role. In this way, they are forced to embark upon a 'career' as a 'chronic mental patient'.

Scheff's assertion that psychiatric classification is both arbitrary and irreversible is supported by Rosenhan's (1996[18]) well-known empirical study in which nine 'sane' people obtained admission to twelve different hospitals by alleging that they could hear voices. Once admitted, they presented their own life history and circumstances, stopped pretending to have any 'abnormal' 'symptoms' and behaved 'normally' and co-operatively. Rosenhan found that:

> Despite their public 'show' of sanity, the pseudopatients were never detected. Admitted, except in one case, with a diagnosis of schizophrenia, each was discharged with a diagnosis of schizophrenia 'in remission'. (p.73)

Rosenhan concludes from this that a label of 'mental illness' once applied is permanent, and notes the serious implications of this finding due to the discrimination resulting from a psychiatric diagnosis.

'Anti-psychiatry' and labelling theory presented a powerful and radical critique of medical psychiatry in the 1960s and 1970s, but since then have been extensively criticised, for example for their limited focus on individuals rather than structural inequalities and oppression (Penfold and Walker, 1983), and for the vagueness of ideas such as 'residual rule-breaking' and its relationship with behaviour viewed as typical of 'chronic mental illness' (Busfield, 1988). Nonetheless, these perspectives

were valuable in highlighting the social and political context of behaviour defined as 'abnormal' (Gomm, 1996) and thus the socially constructed nature of 'mental illness'. Labelling theory also draws attention to the way in which an individual labelled as 'mentally ill' may be kept in that role both by systems of social control and by society in general due to their expectations of and reactions to that individual (Link et al, 1989).

Following criticisms of 'anti-psychiatry' and labelling theory, their dominance in medical sociology has diminished (Turner, 1987:75) and more radical conceptualisations of mental distress have developed, focusing upon structural inequalities, oppression and the role of ideology (Penfold and Walker, 1983). Such ideas can be detected in both the social constructionist and social production approaches outlined below.

Social constructionist view of 'mental illness'

A strong challenge to psychiatry's claim to base its medical model upon objective scientific knowledge has come from the social constructionist perspective. Persuasive arguments to suggest that 'mental illness' and its diagnostic categories are social constructs defined by society's dominant groups in ways which further disadvantage oppressed groups were advanced by feminist writers in the 1970s and 1980s, building upon the work of 'anti-psychiatrists' and labelling theorists (Ussher, 1991).

In her influential work 'Women and Madness', Chesler (1974) highlights ways in which behaviours considered to be signs of 'mental illness' are 'typed' by gender, class and ethnicity. Focusing on gender, she argues that deviations from sex-role expectations are likely to lead to such behaviour being viewed as 'mental illness':

> *What we consider 'madness'... is either the acting-out of the devalued female role or the total or partial rejection of one's sex-role stereotype.* (p.53[19])

---

[18] 'On Being Sane in Insane Places' was first published in 1973.
[19] Original emphasis. Chesler suggests that men are also subject to this rule but only if they act out a female role, due to the devaluation of women's roles in patriarchal society.

Chesler highlights the power of the predominantly male psychiatric profession to define, treat and research 'mental illness' and thereby exercise considerable power over women (p.59). Chesler argues that one of the corollaries of this male domination of psychiatric theory and practice is that their idea of mental health tends to accord to that of *male* mental health. She cites Broverman et al's 1970 study[20] which found that both male and female mental health professionals held different standards of mental health for men and women:

> Clinicians were likely to suggest that women differ from healthy men by being more submissive, less independent... more easily influenced, less aggressive, less competitive... more easily hurt... (p.65)

Furthermore, this study found a high correlation between those behaviours thought to be healthy for adults and for adult men, and those behaviours identified as socially desirable by 'non-professional' participants in other studies. Chesler therefore identifies a double standard operating, from both mental health professionals and wider society, in that "for a woman to be healthy she must 'adjust' to accept the behaviour norms for her sex even though these kinds of behaviours are generally regarded as less socially desirable" (p.65).

From these arguments, Chesler concludes that gender is intrinsically embedded in concepts of 'mental illness', as women's behaviour is pathologised while men's mental health is viewed as 'the norm'. Chesler suggests that this gender bias in the construction of categories of 'mental illness' contributes to explaining the higher prevalence of psychiatric disturbance in women than in men reported by research studies.

While Busfield (1996a) suggests that Chesler's work is limited in its presentation of an oversimplified picture of "male power and regulation over powerless, female patients within the mental health system" (p.231) (thus ignoring the regulation and oppression of men by psychiatry), she also acknowledges its strength in emphasising "the way in which gender permeates constructs of mental disorder" (p.230).

---

[20] Broverman et al's 1970 study asked 46 male and 33 female mental health professionals (including psychiatrists, psychologists and social workers) to complete sex-role stereotype questionnaires in which participants were asked to mark traits representing healthy male behaviour, healthy female behaviour, and healthy adult behaviour (with sex unspecified).

Chesler's arguments have been further developed by other authors. Ussher (1991), for example, highlights the gendered nature of psychiatric discourse in its classification of certain experiences as manifestations of "female disorders" (p.165), such as 'depression' and 'neurosis'. The presentation of psychiatric classifications as universal, i.e. as equally applicable to men or women, and their diagnostic criteria as gender-neutral, is therefore misleading (Busfield, 1996a).

Gender biases in psychiatry's view of what constitutes 'mental illness' are exemplified by the inclusion of a category entitled 'self-defeating (or masochistic) personality disorder' in the revised version of DSM III (DSM III-R) to denote people who repeatedly enter into abusive situations. Only after heavy criticism of such a category as "a female-targeted category that perpetuated the stereotype of abused women as the instigators of damaging relationships rather than the victims of them" (Comer, 2001:103) was it removed.

Both Ussher (1991) and Busfield (1996a) also argue that responses to people's feelings and behaviours are likely to differ according to gender. Ussher notes that "whilst women are likely to be deemed in need of psychological or psychiatric help if they commit a deviant act, men will be deemed in need of legal incarceration, or punishment" (p.171). Busfield contends that this difference may be linked to the gendered nature of agency and rationality, in that Western culture tends to view women as passive and irrational (and therefore powerless and subject to forces out of their control, such as 'mental illness') and men as active and rational (and therefore powerful and responsible for their actions and thoughts).

Some feminist authors (e.g. Chesler, 1974; Penfold and Walker, 1983; Ussher, 1991) also focus upon the way in which psychiatry's power to construct the dominant (masculine) social discourse of 'mental illness' maintains women in subordinated positions by defining them as 'abnormal' rather than as oppressed. Thus is highlighted "the role of patriarchy in sustaining an oppressive system of psychiatric control over women" (Rogers and Pilgrim, 2003:29). Clearly, this argument can also be extended to include class and ethnicity, due to psychiatry's white, male, middle-class bias.

For example, statistics suggesting a higher prevalence of mental distress amongst some minority ethnic communities in Britain may not be valid as they are likely to include misdiagnoses and over-diagnoses of mental distress (Melzer et al, 2002:2). Such errors of diagnosis relate to the biased nature of psychiatric diagnosis in Britain, which "inevitably reflects the myths and stereotypes of the culture from which it derives, including racist ones... the psychiatric view of black people is still influenced by perceptions of alienness, craziness, inferiority, aggression and danger" (Johnstone, 2000:235). This explanation may account for the disproportionately high number of Black people diagnosed with 'schizophrenia' compared with the white population in Britain, and the corresponding over-representation of Black people in the British psychiatric system (Fernando, 1995)[21].

In addition to highlighting ways in which categories of 'mental illness' are socially constructed, reflecting the social norms and prejudices of dominant groups in society (and in particular white, middle-class men), social scientists have also focused upon ways in which structural inequalities and social conditions may play a causal role in the development of distress which then comes to be labelled as 'mental illness'.

Social production approaches to mental distress

Much research and theorising has been undertaken by social scientists and feminist authors to highlight the social origins of experiences of mental distress. Rogers and Pilgrim (2003), for example, argue strongly that symptoms of mental distress have a "social *genesis*" (p. 7), identified as the existence of structural inequalities which result in oppressive conditions with negative psychological consequences for certain groups in society. Epidemiological work also contributes evidence on the social origins of mental distress, and is therefore drawn upon below. Arguments highlighting ways in which mental distress is socially produced amongst oppressed groups are presented in the following sections on social class, ethnicity and gender.

[21] The over-representation of Black people in the British psychiatric system will be discussed in more detail in Chapter Four.

Social class

In capitalist societies, the material conditions in which people live and the resources over which they have control are likely to have differing mental health consequences for members of that society according to their class position. Indeed, strong evidence exists to demonstrate that "in advanced capitalist societies in the second half of the twentieth century there has tended to be an inverse association between social class and mental disorder" (Busfield, 1996a:96-97). Studies have found "considerable evidence in support of a relationship between the particularly difficult social and economic circumstances of working-class life and consequently higher rates of psychiatric breakdown" (Johnstone, 2000:237).

Social selection/drift or social causation?

Various hypotheses have been advanced to explain this class differential, including 'social selection/drift' theory and 'social causation' theory (Rogers and Pilgrim, 2003). Social selection/drift theory is biodeterministic in focus (Rogers and Pilgrim, 2003), suggesting that mental distress is genetically caused and then has an impact upon social class membership in that mental distress causes people to "drift down into or fail to rise out of lower SES groups" (Dohrenwend, 1990:41). However, clear evidence of this social selection/drift theory is not forthcoming from research (Johnstone, 2000).

Social causation theory reverses this argument to highlight ways in which membership of lower socio-economic groups is more likely to lead to mental distress. Epidemiological work in the 1960s and 1970s focused upon the association between social and environmental stress[22] (such as poverty, deprivation and social isolation) and 'mental illness' to provide a social causation explanation of class differences in prevalence rates (Busfield, 1988).

However, Brown and Harris's seminal study 'The Social Origins of Depression' (1978) undertaken in East London offers a sophisticated approach to understanding ways in which social stresses may lead to higher levels of mental distress for

[22] It is noted that difficulties in defining and measuring stress, and differentiating between objective and subjective interpretations of stress, have been highlighted (Turner, 1987).

working-class women[23]. Brown and Harris identified a highly significant class difference in the prevalence of depression[24], with 23 per cent of working-class women having experienced depression in the three months prior to interview compared with 6 per cent of middle-class women participating (although this risk of depression was related to class only for women with children). They propose a causal model of depression from their findings, arguing that social factors play a strong role in causing depression.

Viewing social class as a 'background social factor' in depression, Brown and Harris then define 'provoking agents' as independent variables influencing the onset of depression. Such provoking agents include both discrete life-events, such as losing a job, and ongoing difficulties such as a husband being unemployed. Working-class women were found to be three times more likely to experience at least one such severe life-event relating to their household than were middle-class women. Considerable class differences were also apparent with regard to ongoing household and health difficulties, with 61 per cent of working-class women experiencing at least one such ongoing difficulty compared with 38 per cent of middle-class women. Brown and Harris suggest that these higher rates were due to the environment in which working-class women lived, and were largely out of their control.

However, these different rates of life-events and ongoing difficulties are not enough in themselves to explain the class difference in depression. In addition, Brown and Harris highlight a second set of aetiological variables termed psychosocial 'vulnerability factors'[25], which "are only capable of increasing risk of depression *in the presence of* a provoking agent" (p.47). Again, working-class women were more likely than middle-class women to have at least one of these vulnerability factors, leading Brown and Harris to conclude that the combination of provoking agents and

---

[23] Brown and Harris' research involved a random community sample of 458 women in London, identifying as 'depressed' both women who were receiving treatment for depression and depressed women who were not being treated, and using a comparison group of women in the same community who were not experiencing symptoms of 'depression' (defined by researchers using established assessment scales). Only women and not men were studied as resources were limited, and it was felt both that women would be more likely to agree to lengthy interviews and that fewer interviews would need to be arranged if only women were targeted (due to higher recorded rates of depression amongst women).

[24] Class was defined by Brown and Harris in terms of occupation and education.

[25] These psychosocial vulnerability factors were identified as the lack of an intimate or confiding relationship, loss of a mother before the age of 11, having at least three children aged under 14 living at home, and lack of employment outside the home environment.

vulnerability factors is enough to explain the class difference in the risk of developing depression identified amongst women with children[26].

Despite criticisms of Brown and Harris's work, including their inability to make gender comparisons due to the absence of men from the study sample (Rogers and Pilgrim, 2003) and its lack of generalisability across time and place due to its acceptance of society's structure and culture as 'given' (Busfield, 1996a), it remains a very important contribution to understanding social causes of mental distress. Their work demonstrates the social and environmental pressures on working-class women and their possible psychological consequences (Davis et al, 1985).

Brown and Harris also offer a more complex level of understanding of the link between stress and mental health by focusing upon how stress is socially mediated, i.e. how social and cultural factors influence the way in which people respond to difficulties. Further, they avoid an over-emphasis on individual psychology by identifying vulnerability factors as 'socially generated', due to women's social circumstances (Busfield, 1988:526).

More recent studies have tended to focus upon socio-economic status (SES) as a better predictor of mental distress than social class. Lewis et al (1998), for example, undertook analysis of data from 9,570 adults in the 1993 British National Survey of Psychiatric Morbidity to explore the association between socio-economic status and the prevalence of 'neurotic disorder'. They used three measures of socio-economic status: social class (as defined by the Registrar General system), educational qualifications, and car access and housing tenure (as a measure of income or standard of living), and found the latter to be most strongly associated with the prevalence of mental distress (p.608).

Similarly, Melzer et al (2002) found that of the nine large community studies[27] included in their systematic review of links between social position and 'neurotic

---

[26] A further set of variables, called 'symptom-formation factors' are identified by Brown and Harris, which are said to influence the nature and severity of depression experienced (rather than the risk per se of developing depression). These include grief, hopelessness and low self-esteem. Brown and Harris suggest that low self-esteem is a common feature of all four vulnerability factors highlighted, due to the powerful role identities involved.

disorders', eight studies identified an association between at least one marker of 'less privileged social position'[28] and higher rates of 'neurotic disorders'. However, they found that "occupational social class was the least consistent marker for higher prevalence rates" while "having less education and being unemployed were the most consistent independent social position markers" (p.2)[29]. Melzer et al identify a probable causal relationship between deprivation, material disadvantage, poverty, unemployment, and mental distress.

Other research highlights unemployment as a strong socio-economic pressure which may be experienced very negatively, particularly in capitalist societies where work and economic productivity are seen as important aspects of social identity (Johnstone, 2000). Unemployment's negative impact upon mental health results from a combination of social and environmental factors, including "objective and subjective losses; chronic socio-economic adversity; absolute as well as relative poverty; and the indirect effects of poor nutrition, inferior physical health and raised levels of local environmental stressors" (Rogers and Pilgrim, 2003:119).

Ethnicity

Oppression on the basis of ethnicity may also play a role in the development of mental distress, for example due to the impact of racial discrimination (Busfield, 2000; Thompson, 1993) and institutional racism in Western society (Fernando, 2002).

Melzer et al's (2002) systematic review of population-based studies of 'common mental disorders' amongst Black and minority ethnic groups identifies prevalence rates similar to or higher than those in the general population[30]. Risk factors identified by Melzer et al (although not confirmed across all studies included) suggest a strong contribution of social factors to mental distress within minority ethnic communities in Britain, with oppression due to racism compounded by low

---

[27] These studies were conducted in Britain, North America, Holland and Australia.
[28] These markers were defined as occupational social class, employment, education and material circumstances (p.2).
[29] 'Having less education' is defined in this study as having left full-time schooling before the age of 16.
[30] For example, higher prevalence rates of depression in Caribbean and African groups, of 'anxiety' in the Irish-born population, and of 'phobias' in Asian groups (Melzer et al, 2002:10).

socio-economic status and social isolation. These risk factors are summarised in Figure 1.

Figure 1: Risk factors for the development of mental distress amongst Black and minority ethnic communities in Britain

- Absence of full-time worker in the household
- Unemployment
- Low standard of living, financial difficulties
- Migration before the age of 11
- Being a lone parent
- Victimisation, personal attacks, and racial harassment
- Problems with the police
- Discrimination in housing and employment
- Absence of a confidante, absence of parents-in-law
- Social isolation, small primary group and perceived lack of social support

(Source: Melzer et al, 2002:10-11)

The likely interaction between ethnicity, social class and gender has not been studied in depth, as these social factors are often considered separately in research studies (Rogers and Pilgrim, 2003).

Gender

With regard to gender, research in both hospital and community settings has found that women are more likely than men to experience depression, anxiety, self-harm and eating distress (Johnstone, 2000). Community studies have shown that women are twice as likely to experience depression as are men (Davis et al, 1985), and that mothers of young children are particularly vulnerable to experiencing depression (Penfold and Walker, 1983).

Busfield (1996a) argues that to understand higher rates of mental distress experienced by women compared with men, structural and power inequalities between men and women must be considered, as these impact upon women's work, their role within the home, and their experiences as wives. For example, Johnstone suggests that the higher prevalence of certain forms of mental distress amongst women may be due to the oppressive social and economic circumstances of many

women's daily lives, such as "poverty, low-paid and low-status jobs, lack of support in child-rearing, isolation within the home, increased vulnerability to domestic violence and sexual abuse... and the conflicting expectations of women's changing roles" (p.117). Marriage has been identified as a factor increasing women's risk of experiencing mental distress (Turner, 1987), as has women's devalued role within the family (Davis et al, 1985). Gender-related social factors increasing women's susceptibility to distress are clearly compounded by class (see p.26).

Women's experiences of abuse and trauma have also been shown to impact upon their mental health.

Impact of abuse and trauma

Busfield (1996a) defines trauma as "extreme, severe and exceptional experiences" that "often involve threats to life or bodily integrity, or a close personal encounter with violence and death" (p. 211), such as war, torture, sexual abuse and domestic violence. A very strong correlation between traumatic experiences and the development of mental distress has been identified (Kinderman and Cooke, 2000:32).

For example, research has found that up to 50 per cent of women using mental health services have experienced childhood sexual abuse, compared to approximately one in eight women in the general population (Johnstone, 2000). A range of 'trauma-related syndromes' has been identified amongst childhood abuse survivors and women who have experienced domestic violence, including "parasuicidal behaviour, drug or alcohol abuse, self-harm and depression" (Rogers and Pilgrim, 2003:144). Johnstone (2000) challenges the validity of applying a medical model to such distress, arguing "what sense does it make to see all these women as suffering from illnesses with biological causes, as opposed to traumas with psychological consequences?" (p.116).

Penfold and Walker (1983) suggest that society's ideologies and structures (including psychiatry, the criminal justice system and the family) contribute to these levels of violence towards women, and highlight historical and cross-cultural views

of women as "non-persons who have no legal rights, have status only as men's property... to be used for men's pleasure, and are destined to serve men" (p.169).

Rogers and Pilgrim (2003) emphasise the interwoven nature of social influences on mental health, noting research findings that "early social insults (poverty, neglect and abuse) predict poor mental health in later life" (p.234). Childhood disadvantage, and the higher risk of corresponding emotional problems, is compounded by other forms of disadvantage such as poor school performance and attendance, lower levels of academic achievement, and corresponding labour market disadvantage (shown above to be related to higher levels of mental distress).

Hence the social production theoretical viewpoint suggests that the existence of structural inequalities in capitalist society results in oppressive conditions for certain groups, such as women, Black people and working-class people, which then have negative mental health consequences.

Social construction and social production: contradictory or complementary viewpoints?

Busfield (1988) notes that some feminist writers have been criticised for advocating both social constructionist and social production viewpoints on women's experiences of mental distress. However, she argues that both positions are tenable, with the social production viewpoint focusing upon the social aetiology of mental distress, while the social constructionist argument is concerned with the way in which this distress is classified and social responses to this classification. Ussher (1991) combines both viewpoints to argue that "misogyny makes women mad either through naming us as the 'Other', through reinforcing the phallocentric discourse, or through depriving women of power, privilege and independence" (p.7).

These arguments are applicable not only in relation to gender and conceptualisations of mental distress, but also to class and ethnicity. It is clear from the evidence presented above both that social conditions arising from structural inequalities increase the risk of members of certain oppressed groups experiencing mental distress, and that these structural inequalities when reflected in society's institutions

then have an impact upon the likelihood of this distress being identified and labelled as indicative of 'mental illness' and 'treated' accordingly.

Social influences on course of mental distress

Structural inequalities also influence people's experiences once their mental distress comes to the attention of mental health services (Williams, 1999), with oppressed groups receiving differential treatment from psychiatry (reflecting society's dominant values). With regard to working-class people, research has found that "severer diagnoses are given to working- than to middle-class patients, regardless of symptoms;... the former are seen as having a poorer prognosis... and... are most likely to receive the 'disabling' rather than the 'empowering' psychiatric treatments" (Johnstone, 2000:238), namely drugs and ECT. 'Talking treatments' such as psychotherapy are offered less frequently to poorer people, Black people, older people and men (Rogers and Pilgrim, 2003:213-214).

Similarly, feminist writers (e.g. Chesler, 1974; Davis et al, 1985) have highlighted the differential treatment of women within the psychiatric system, including the application of "evaluative social and sexual standards" (Davis et al, 1985:82). Penfold and Walker (1983) emphasise the disproportionate number of women receiving psychotropic medication in comparison with men, and suggest that this is due to psychiatry's social control role in returning women to their traditional sex-roles: "a woman is drugged to make her more 'feminine', more accepting of her traditional role, or less disturbing to her husband" (p. 206).

More recent work has identified that women in England are twice as likely to receive ECT as are men, including under section, with women over 65 making up the largest group of people given ECT (Johnstone, 2000). Women have also been over-represented amongst patients who are compulsorily admitted and treated (Hatfield and Mohamed, 1994; Williams, 1999[31]).

---

[31] It is noted that this trend of women's over-representation in compulsory admission has now been reversed, since the shift to community care in the 1990s (Payne, 1996).

Service user/survivor development of social perspectives

The 'anti-psychiatry' critiques of the medical model of 'mental illness' and corresponding development of social theory and research on both the social construction of categories of 'mental illness' and the social origins of mental distress, have strongly influenced theorising by the mental health service user/survivor movement in both Britain and the USA.

For example, the influence of 'anti-psychiatry' writers and social constructionist viewpoints is clear in the writings of American survivors such as Chamberlin (1988[32]). Her influential work on the need for alternative, user-controlled mental health services focuses on psychiatry's social control role and views 'mental illness' as a social status rather than as a result of any genetic or neurochemical 'defect'. Chamberlin argues against labelling people's emotions and experiences as part of a 'disease' process if people are to be supported to understand and deal with these.

The social model of disability advocated by the UK disability movement (Oliver, 1986, 1996; Zarb, 1992) has also contributed to mental health service users' development of social approaches to mental distress. This social model draws a terminological distinction between 'impairment' and 'disability', asserting that individuals are disabled not by their physical impairments but by society's reaction to and treatment of individuals as a result of those impairments. This model therefore defines disability as "a social relationship... created by a disabling environment and disabling attitudes" (Stone and Priestley, 1996:701). Oliver (1996) outlines the conceptualisation of disability within this social model:

> It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to adequately ensure the needs of disabled people are fully taken into account in its social organisation... disabled people as a group... experience this failure as discrimination institutionalised throughout society. (p.33)

Although the social model of disability has been criticised for masking the psychological and physical 'pain of impairment' (e.g. Morris, 1991), and its merits are debated in the disability literature (e.g. Shakespeare and Watson, 1997), it nonetheless provides a powerful means of conceptualising the way in which

---

[32] First published in America in 1977.

disability is imposed upon people by society, rather than being an inherent characteristic of individuals (Moore et al, 1998).

Such an argument can clearly be extended to mental health, in that while someone may be experiencing mental distress, they are 'disabled' and oppressed not by the distress but by society's negative and discriminatory reaction to that distress (including its application of socially constructed categories of 'mental illness').

Some mental health survivors, including Beresford et al (1996), suggest that the direct application of the social model of disability to mental health users/survivors might not be appropriate. Differences in the situation of disabled people and people with experience of mental distress, for example the additional oppression experienced by mental health service users via coercive mental health legislation, and the strong links drawn by the media and the general public between diagnoses of 'mental illness' and 'dangerousness'[33], mean that a social model of mental distress is likely to incorporate some issues distinct from those emphasised by the social model of disability.

Beresford et al (1996) therefore draw upon elements of the social model of disability, as well as much of the theoretical work discussed above, to propose a "social model of madness and distress" (p.211) that highlights:

- the social causes of our madness and distress;
- the medicalisation of our experience and distress;
- the destructive and discriminatory response to it from both psychiatry and broader society;
- the need for a *social* response to the distress and disablement which survivors experience, addressing the social origins and relations of their distress…;
- the need for survivor-led alternatives to prevent distress and offer appropriate support for survivors. (p.211[34])

Hence, in addition to assimilating social production theories and critiques of psychiatry's medicalisation of distress, Beresford et al include practice elements in their model by emphasising the need for social responses to distress and survivor-led alternatives to current professional models of support.

---

[33] This erroneous linking of 'mental illness' with 'dangerousness' is discussed in Chapter Four.
[34] Original emphasis.

Conclusion

The medical model of 'mental illness' has been shown to result from the medical profession's power and authority to historically assert its legitimacy and dominance in 'treating' 'insanity', rather than from successful identification of physical origins of distress via scientific endeavours as claimed by psychiatry. This medical model is untenable on a number of levels. It assumes a biological or genetic basis for mental distress, yet this assumption is unsubstantiated by evidence. The medical model relies partly for its legitimacy upon a diagnostic and classification system similar to that used in general medicine. However, both the validity and reliability of psychiatry's diagnostic systems, as exemplified by the APA's DSM, have been shown to be poor. Rather than being scientifically-based and objective, psychiatry's 'categories' of 'mental illness' have been shown to be socially and politically influenced evaluative concepts, resulting from power struggles between groups with vested interests and reflecting structural inequalities and oppression in society.

Damaging consequences of the medical model's predominance include: the individualising and pathologising of problems which may have social origins; denial of the validity of people's feelings and experiences, by interpreting these as 'symptoms' of 'illness' and attempting to suppress them via physical 'treatments' with severe side-effects; and the systematic oppression experienced by people with a diagnosis of 'mental illness'.

Psychiatry relies upon perpetuating this medical approach to 'mental illness' to maintain its powerful position in 'treating' people experiencing mental distress, its credibility as a branch of medicine, and its social control role as an agent of the state contributing to the political 'status quo' (Penfold and Walker, 1983). The conceptual and empirical flaws in the medical model highlighted above therefore have considerable significance for the legitimacy of psychiatry's theories and practices, throwing both into question (Johnstone, 2000:76-77).

Powerful arguments have been advanced by social scientists to challenge this medical model. Social factors resulting from structural inequalities can be seen to play a role in experiences of mental distress at different levels: by influencing the

likelihood of someone developing mental distress, due to their membership of a certain social group and the social, political and cultural context in which they live; by shaping how such distress becomes defined as 'mental illness', which involves socially constructed categories reflecting the assumptions of society's dominant groups; and by influencing the way in which people experiencing mental distress are treated once they receive a label of 'mental illness' by both psychiatry and society.

These arguments highlight a 'triple jeopardy' for oppressed groups in society in that they are more likely to develop mental distress due to their structural position in society, this distress is then more likely to be diagnosed as 'mental illness', and once such a diagnosis has been applied members of oppressed groups are likely to receive poorer treatment and a more negative 'prognosis' with regard to recovery from distress than members of dominant social groups.

The nature of oppression and power relations is therefore critical to understanding the experiences of people in mental distress. It is important to establish clear theoretical and conceptual frameworks of oppression, power and professional power to inform subsequent analysis and discussion in this dissertation, and this work is undertaken in the following chapter.

Chapter Two: Conceptualising oppression, power and professional power

Introduction

Empowerment strategies engaged in by people with experience of mental distress are a focus of this dissertation. Meanings of oppression and power, as key concepts underpinning the notion of empowerment (Mullender and Ward, 1991), are explored in this chapter both to provide a framework for considering mental health service users' experiences and to contribute to subsequent discussions of empowerment. The nature of professional power is also examined due to its significant role in the lives of many people experiencing mental distress.

Conceptualising oppression

Oppression is a concept that has been defined in a range of ways by social scientists (Abberley, 1987; Keating, 1997). Debates include: the extent to which oppressive relations are considered as fixed and unidirectional, or as fluid, dynamic interactions; consideration of whether oppression results from individuals' actions or structural conditions; and analysis of forms of oppression either as separate entities located within a 'hierarchy of oppression' or as interconnected elements of people's 'lived experience'.

Nature of relationship between 'oppressor' and 'oppressed'

Some view oppression as a dichotomous, unidirectional relationship between two distinct groups, 'the oppressors' and 'the oppressed' (Dominelli, 2002), drawing on an essentially Marxist view of power. Freire (1972), for example, identifies the prescriptive imposition of one group's will upon another as a basic element in this relationship. Similarly, both Giddens (1991) and Braye and Preston-Shoot (1995) define oppression as the exercise of power by one group over another in a way that limits that group's life chances and opportunities.

However, this binary opposition of 'the oppressors' and 'the oppressed' has been challenged (Hammersley, 1995; Keating, 1997). Young (1990) suggests that "group differences cut across individual lives in a multiplicity of ways that can entail privilege and oppression for the same person in different respects" (p.42). For example, Duckett (1998) argues that the British disability movement, an identifiably oppressed group, has nonetheless behaved oppressively towards other oppressed groups such as Black people, and Beresford (2000) has highlighted prejudice from the disability movement against people experiencing mental distress.

The view of oppression as a one-way exercise of power by 'the oppressors' over 'the oppressed' has also been criticised for ignoring the capacity of oppressed people to resist oppression (Brittan and Maynard, 1984:223). Conceptualising oppression instead as a more fluid, interactive process means that resistance both by individuals and groups is possible (Dominelli, 2002:9).

Hence, while oppression may occur between groups of people in society, it is important to recognise that oppressive relations are fluid, dynamic and multi-dimensional. These relations are likely to change according to time and place (Keating, 1997) and to involve constant interactions between people attempting to exercise power via a range of behaviours (Dominelli, 2002). This fluidity and complexity renders the binary 'oppressor'/'oppressed' model inadequate in conceptualising oppression (Thompson, 2001).

Agency or structure?

Viewing oppression in terms of the actions of a particular group of people with power over another less powerful group has also been criticised for failing to acknowledge structural elements of power (Dominelli, 2002).

A structural view is propounded by authors such as Young (1990), who defines oppression thus:

> Oppression... is structural, rather than the result of a few people's choices... Its causes are embedded in unquestioned norms... in the assumptions underlying institutional rules and the collective consequences of following those rules... Oppressions are systematically reproduced in major economic, political, and cultural institutions. (p.41)

Such a structural definition removes any conscious agency from the exercise of oppression in so far as people may be reproducing oppression in their everyday lives yet would not identify themselves as "agents of oppression" (Mullaly, 1997:145).

However, the way in which intentionality and agency are attributed to macro structures in such arguments can be criticised (Keating, 1997; Payne, 1997). Brittan and Maynard (1984) contest this conceptualisation of "clockwork oppressors, wound up by some inexorable determining mechanism that resides in the 'system'" (p.212). They argue that propounding a solely structural view of oppression absolves people from their responsibility for oppressive actions, and therefore combine individual and structural elements of oppression in their definition:

> All racist and sexist practice involves a power relationship in which the subjectivity of personal experience is intertwined with the objectivity of collective and political relationships. (p.213)

Similarly, Giddens' structuration theory emphasises both structure and agency, viewing them as 'two sides of the same coin' whereby "human agency produces structures which simultaneously serve as the conditions for reproduction of human agency in a continuing process" (Clegg, 1989:139). Such a 'dual perspective' highlights the complex and multi-faceted nature of oppressive relations.

Separate or inter-related forms of oppression?

With regard to different forms of oppression, there are debates about the extent to which oppressions should be analytically separated out into categories such as class, ethnicity, gender, disability, sexuality and age. Marxist theory identifies oppression as resulting from the ownership of means of production, whereby capitalist employers exploit workers for their labour (Marx, 1963). However, attempts by Marxist writers to 'fit' class explanations of oppression to gender and ethnicity have been criticised for failing to recognise that gender and ethnicity qualitatively alter the nature of oppression (Brittan and Maynard, 1984).

The idea of considering forms of oppression separately, or in some form of hierarchy according to their salience, can be criticised as both divisive, masking similarities between groups, and simplistic, ignoring the interconnected way in which different aspects of people's lives form their experiences (Keating, 1997). The need to consider multiple oppression, for example experienced as a result of class, ethnicity and gender, as "facets of an overall edifice of power and dominance" (Thompson, 2001:11), is also important in developing a holistic understanding of oppression as 'lived experience' for individuals.

Common themes can be identified across forms of oppression, including: the social control function of dominant ideas in maintaining oppression; power relations; the use of coercive activities; restriction of personal freedom and denial of rights; social exclusion; the creation of (supposedly biologically-based) hierarchies to preserve dominant interests; prejudice and stereotypes; interplay between psychological, cultural and political dimensions of oppression; and the possibility for resistance to oppression (Keating, 1997:18; Thompson, 1993:33). All of these themes are relevant to the experiences of people labelled as 'mentally ill' in British society, as explored in Chapter Four.

Multi-dimensional approaches to oppression

Multi-dimensional models of oppression which attempt to conceptualise processes of oppression and the varying levels at which they operate include Young's (1990) 'faces' of oppression, Thompson's (1993) personal, cultural and social (PCS) model and Keating's (1997) integrated model of oppression.

Young's 'faces' of oppression

Young (1990) identifies a group of concepts and conditions, as 'faces' of oppression. These are: exploitation (specifically of people's work capacities by those who own the means of production); marginalisation in terms of exclusion of particular groups from the labour market; powerlessness (specifically in relation to the privileging of professionals over non-professionals in the workplace); cultural imperialism (namely the way in which dominant groups are able to render other groups invisible while singling them out as 'Other'); and systematic violence.

Young's 'faces' of oppression can be seen to have some relevance for people with experience of mental distress. In particular, marginalisation from the labour market, and cultural imperialism, are oppressive phenomena commonly experienced by mental health service users.

However, Young's model can also be criticised. She suggests that the presence of any of the five 'faces' suffices for a group to be oppressed, but it is not clear whether these 'faces' are causes, manifestations or consequences of oppression. Young presents these as criteria for determining the 'presence' of oppression, rather than as a theory of oppression, thereby acknowledging that her approach is descriptive rather than analytical.

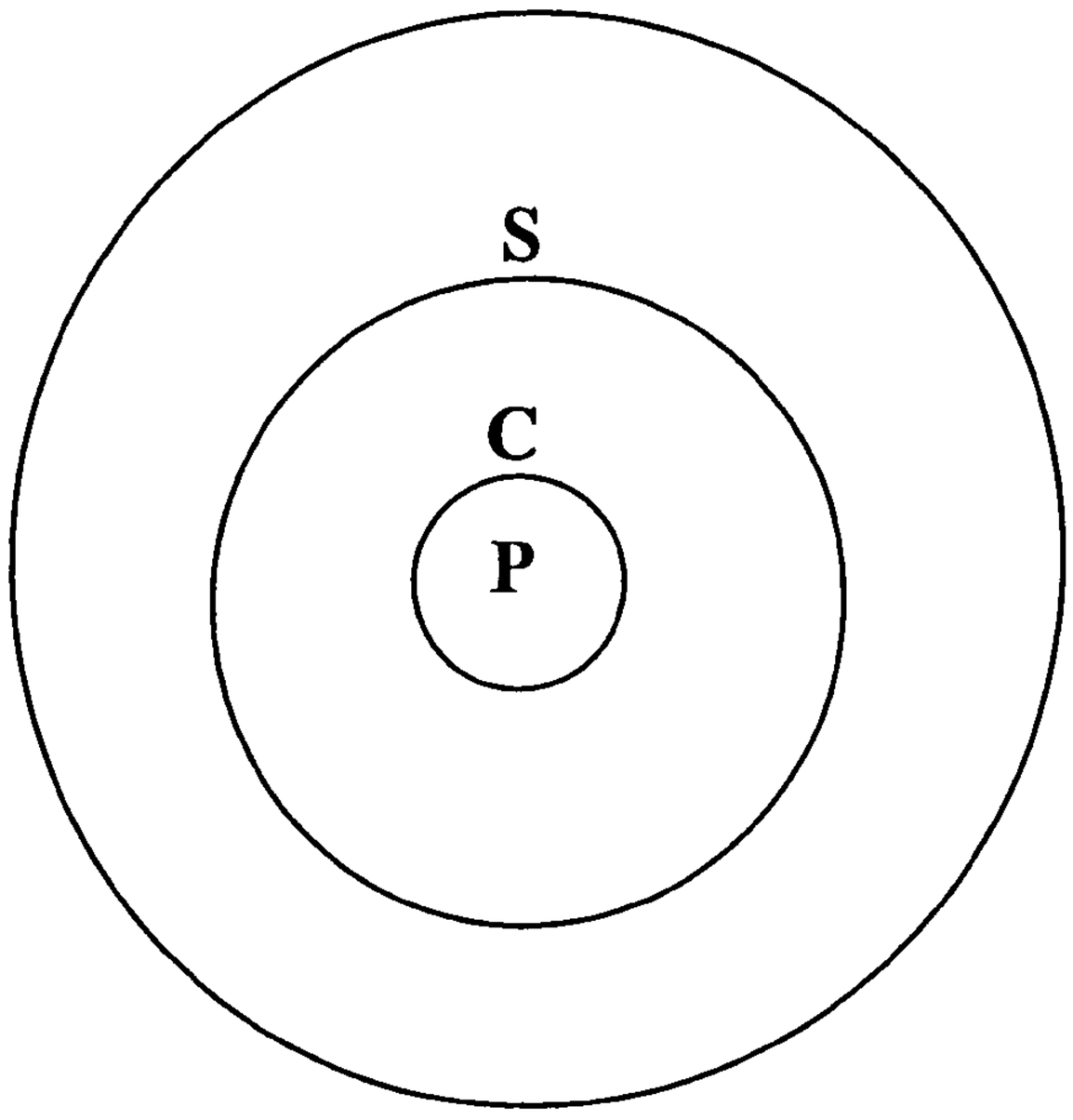
Further, her definitions of exploitation and powerlessness are very specifically related to the employment market, possibly referring to a 'Golden Age' when work conditions were believed to have been more stable and the market for employment less competitive. The overall model does not therefore offer a sufficiently comprehensive and well-developed framework to apply to the oppression of people with experience of mental distress in contemporary society.

Thompson's PCS model of oppression

While Young presents 'faces' of oppression, Thompson's (1993) model demonstrates the operation and interaction of personal, cultural and structural levels of oppression (Figure 2, p.42).

The *P* level represents the personal level of attitudes, actions, thoughts and prejudices, and is embedded in and influenced by culture. The *C* level refers to the cultural norms and social values representing society's influence and interests, which are internalised via socialisation processes. The cultural level is in turn embedded in the structural level of oppression (*S*), which Thompson defines as "the interlocking matrix of social divisions and the power relations which maintain them" (p.21).

Figure 2: Thompson's PCS model of oppression



(Source: Thompson, 1993:19)

Thompson views the relationship between levels as an ideological one. Ideology, which he defines as a 'norm-establishing' group of ideas associated with a set of social arrangements, both functions as "the vehicle of 'cultural transmission' between the *C* and *P* levels" and "explains how the *C* level reflects, maintains and protects the *S* level by presenting social divisions as 'natural' and 'normal' and thus desirable" (p.27). Thompson therefore gives explanatory power to ideology in his model of oppression.

This model integrates the individual and structural levels of oppression, and includes the mediating role of culture, to consider how these interact in individual oppressive events. However, Thompson's approach has been criticised as over-simplistic both in his conceptualisation of culture as a stable and dominant constellation of social values, and in the assumptions implied in a concentric view of oppression about the necessary influence of each level on the others (Payne, 1997:244).

Keating's integrated model of oppression

Keating (1997) argues that "whenever one encounters a situation of oppression it encourages analysis of all its dimensions" (p.36) and therefore proposes a more sophisticated model of oppression consisting of different dimensions operating at a range of levels. Three dimensions of oppression are identified:

i) Socio-political

This dimension refers to "the way in which oppression is legitimated and institutionalised... the ways in which power is used to dominate and assign differential status to groups" (p.36). The political aspect refers to "the systems and structures of power and how they are linked to oppress" (p.40), while the social aspect is defined as "the way in which these systems developed over time and how they affect certain groups in society" (p.40). Economic factors such as resource distribution are also an aspect of this dimension of oppression (Thompson, 1998)[35].

ii) Socio-cultural

Socio-cultural oppression relates to "the way in which culture is used as the mediator and carrier of oppression" (p.40). Processes of socialisation and differentiation are key in considering both how groups are created and how identity and 'difference' are constructed (see p.45-46), in that culture provides the desired images from which we both develop ideas of 'otherness' and formulate assumptions and stereotypes. Language also plays a role in defining social categories and divisions (Keating, 1997).

Socio-cultural oppression can be played out unconsciously, as assumptions and values become part of 'everyday life' (as discussed on p.47).

iii) Psychological

Psychological oppression is viewed as "how people experience oppression subjectively and how the basic dimensions of life are violated" (Keating, 1997:36). This dimension highlights what oppression does to society collectively, to people

---

[35] Conversely, the socio-political dimension also includes ways in which oppressed groups have organised themselves in society and have used power to challenge oppression (Keating, 1997).

who experience oppression, and to oppressing groups. Freire (1972) asserts that oppression harms all involved, as a dehumanising force for the whole of society. Dalrymple and Burke (1995) use the example of sexism to illustrate this point, arguing that "sexism distorts the relationship between men and women and in the process both are violated" (p.16).

Keating (1997) therefore offers the following multi-dimensional definition:

> ...oppression is about... how divisions in society are constructed, how power is used to dominate, how language is used to construct meaning, and how people experience and understand all these processes subjectively. (p.23)

Keating's remarks on oppression's impact upon people who experience it are powerful and reflect comments of some mental health service users in research studies (see p.122):

> It brings a sense of pain, grief... and feelings of worthlessness. Oppression can also evoke anger and rage that may lead to... resistance. More often it... leads to **internalised oppression**... when people... have distorted views of themselves, they do not believe in their own self worth and may discount their own experiences in deference to the oppressors. (p.42)

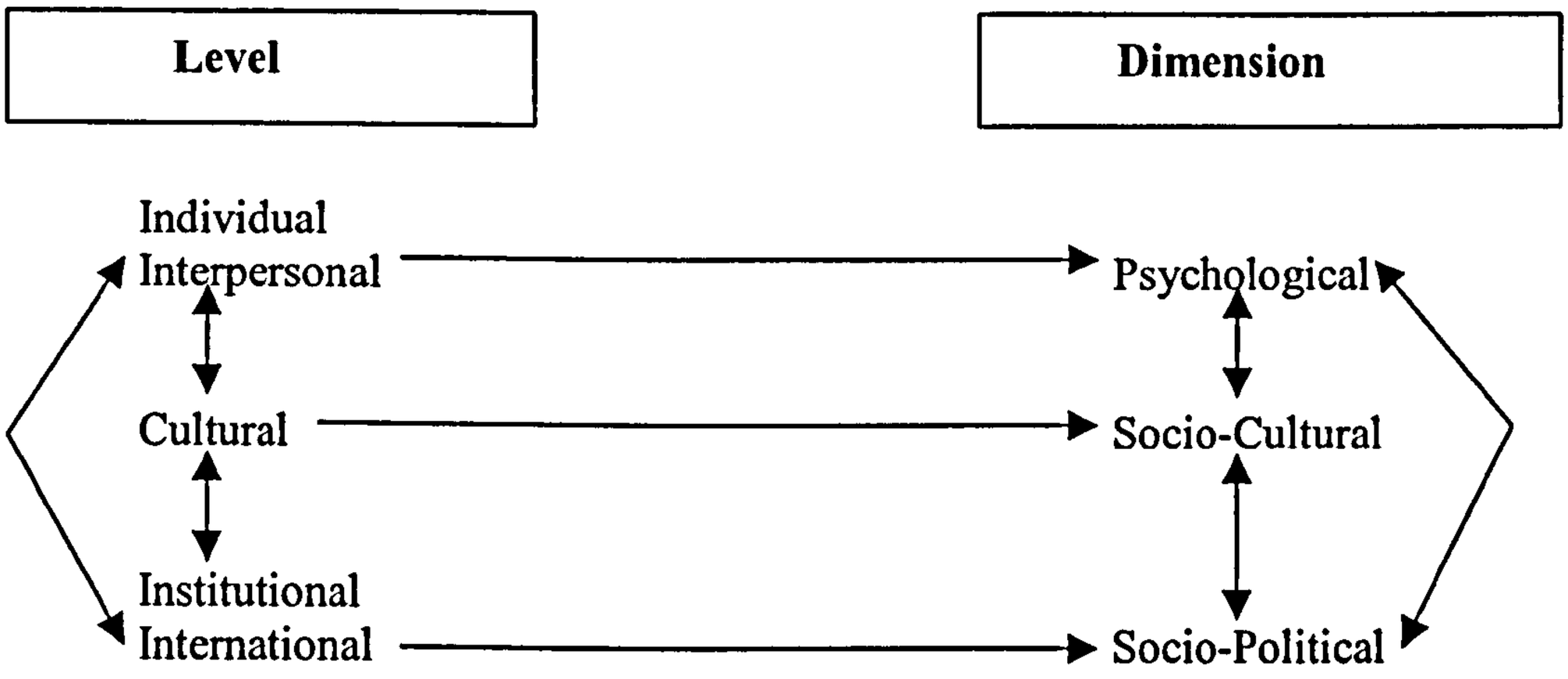
Freire (1972) similarly argues that such internalised oppression may lead to low self-esteem and self-image, inducing 'fear of freedom' (i.e. of autonomy and self-responsibility) amongst oppressed people. This internalised oppression may then contribute to reproducing oppression, by preventing people from "developing a sense of entitlement" (Marks, 1999:619). People may also feel unable to be open about their membership of oppressed groups, for example as disabled people (Abberley, 1987), so that they are not exposed to the negative stereotypes and material disadvantages which accompany oppression.

These dimensions of oppression operate at four levels: individual/interpersonal, cultural, institutional, and international (Figure 3)[36].

---

[36] Keating includes 'international', despite its apparent inconsistency with the other three levels identified, both due to the way in which oppressed people can be treated when travelling internationally (for example the treatment of Black people, and people living with HIV), and to the way in which international organisations such as Amnesty International and Stonewall fight to counteract oppression.

Figure 3: Keating's dimensions and levels of oppression



(Source: Keating, 1997:37)

Keating argues that each of the dimensions on their own cannot result in oppression, as oppression requires "a power base, a social base and a personal base to have any impact" (p.38). Viewing oppression as "the creation and use of mechanisms which sustain unfair dominance" (p.30), the processes he identifies which allow the reproduction of society's institutions and ideas and thereby link these dimensions together are social stratification and its subprocesses of domination and differentiation:

> **Stratification** is how groups are assigned differential status and power, **domination** refers to how power is used to oppress, and **differentiation** refers to the processes involved to give significance to human attributes such as skin colour... and how these are used to create groups and make distinctions between them. (p.38)

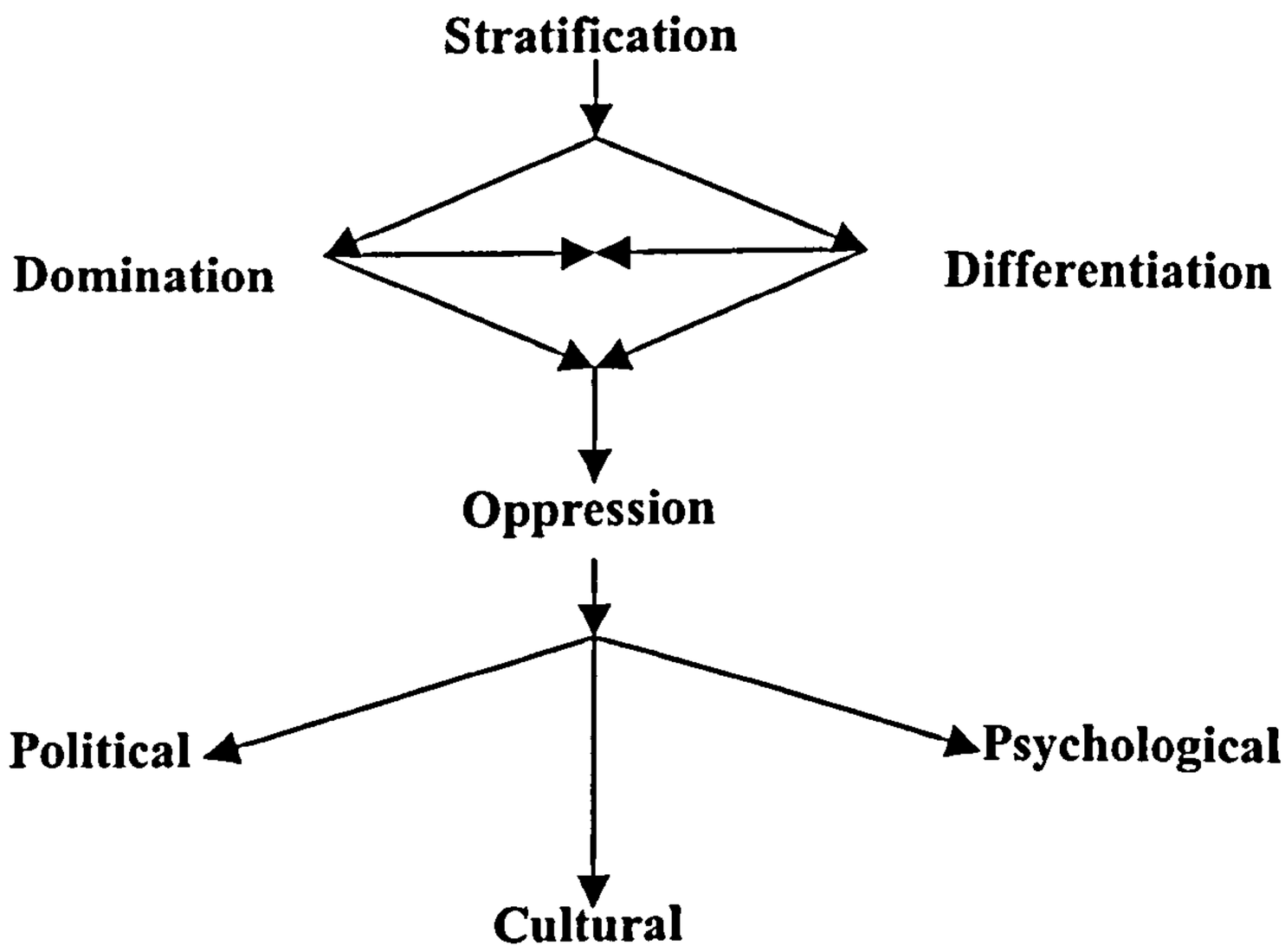
He suggests that the way in which these processes operate and reproduce inequitable social relations must inform an analysis of oppression. Keating does not elaborate any further on the way in which these mechanisms operate. However, others have outlined the way in which social stratification on the basis of divisions such as class, gender, ethnicity, age and disability operates to differentiate between people and locate them in different positions within society's structural network of institutions and relations (Thompson, 2001).

Oppressive consequences of such differentiation and domination result from their evaluative and oppositional nature, with membership of one group defined as superior and more socially desirable than the other (Dominelli, 2002). Certain

groups are constructed as 'other' and therefore as inferior or pathological in comparison with dominant groups, such that "the translation of difference into otherness (reinforces) the power of the dominant identity in a given society" (Stainton, 1998:127).

Keating therefore presents an integrated model of oppression (Figure 4). While he acknowledges that different forms of oppression exist, he argues that similar processes and complexities underpin all forms and that an integrated framework of analysis is therefore valuable.

Figure 4: Keating's multi-dimensional model of oppression



(Source: Keating, 1997:39)

Keating's dimensions are similar to the levels included in Thompson's PCS model. Nonetheless, Keating's multi-dimensional approach offers the most sophisticated model of oppression of those described, in that it attempts to incorporate dimensions of oppression, to consider the range of levels at which these might operate, and to outline processes which link these dimensions together to reproduce unequal social relations. This model will therefore be used in Chapter Four to inform consideration of the range of ways in which oppression influences the lives of people with experience of mental distress.

Ideology and discourse

The concept of 'ideology' has developed from Marxist thought on 'false consciousness', defined as "a set of ideas that serves to conceal the exploitative nature of capitalism from the proletariat" (Thompson, 2001:23). Such a conceptualisation, based on the assumption that a real 'truth' currently masked by capitalist domination can be uncovered, has been criticised by authors such as Foucault (1980) (see p.55).

However, the more common current usage of 'ideology', i.e. as "the totality of processes which form and maintain the social awareness of the individual members of that society" (Fook, 2002:56) can be seen to play an important role in sustaining oppression via the social control function of ideas. Dominant ideology, such as patriarchy and capitalism, "has the effect of 'legitimising the status quo' and thus justifies, protects and reinforces those social arrangements and the power relationships inherent within them" (Thompson, 2001:26-27). In contrast, countervailing ideologies also exist to oppose such dominant ideologies (for example feminist ideologies).

Ideological 'devices' operate to establish legitimated assumptions and ideas, for example what is considered 'normal' and therefore 'abnormal'. In addition, "claims to objective differences and the reification of social phenomena as 'natural facts'" (Stainton, 1998:127), such as identifying women's 'natural' association with the home and family, are used to justify oppression of certain groups. Stereotyping, as an extreme and rigid form of typification, is also used ideologically to justify and maintain oppression (Thompson, 2001).

Ideologies of 'difference' can result in objectification and dehumanisation, such that people are viewed as animals or objects and deprived of autonomy and human dignity (Kuper, 1974). Hence, ideologies can be seen as powerful components in maintaining oppression, due to their appearance as 'natural', and their embeddedness in everyday life and in people's consciousness (Brittan and Maynard, 1984).

As 'discourse' is sometimes used in the same way as ideology, it is important to distinguish between the two concepts. Common contemporary usage of the term 'discourse' tends to refer to "the context in which individual people live, in particular the linguistic context, and how this not only frames our understandings of our social world, but also how we construct our own identities within it and through social relations" (Fook, 2002:63). As such, discourses can contribute to recreating and maintaining oppression, for example medical discourse which presents disability as individual pathology (Oliver, 1986).

Discourse, defined as linguistic systems of communication, is therefore a similar concept to ideology (in its more general sense) in its focus upon power and symbolic representations, and both are significant in exploring the nature of oppressive relations.

Foucault's (1980) use of the term 'discourse' is broader than a focus on language use, referring to specific bodies of knowledge and associated power relations that become constituted and gain predominance at particular points in time (as discussed on p.55-56).

Responses to oppression

Attempts to categorise and schematise the range of responses to oppression have been made, using a framework from accommodation and compliance through to resistance (Dominelli, 2002; Mullaly, 1997). Acceptance, whereby oppressed groups internalise the dominant social norms and values, may lead to people reproducing their oppression, while others may use accommodationist strategies, "balancing a mild critique of the system with obtaining the best compromises from those who endorse it or hold power over them" (Dominelli, 2002:11). However, both individual and collective resistance to oppression is also possible, ranging from subversion to direct action. Such resistance may also include oppressed groups developing positive identities for themselves (Brittan and Maynard, 1984) via a 'politics of difference' which celebrates diversity (Mullaly, 1997).

As the above exploration of oppression demonstrates, power relations are central to all forms of oppression (Thompson, 1993) and will therefore be explored in the next section.

Conceptualising power

Similar to oppression, power has been defined in varying ways within different theoretical frameworks (Thompson, 1998). Indeed, it can be argued that "it is part of the power struggle in society to decide how power itself should be conceived" (Hoy, 1986:144).

Power has been defined both as a negative and a positive force (Dominelli, 2002), as finite in amount (a 'constant sum' conceptualisation) or as an ever increasing social resource (a 'variable sum' approach) (Wilkinson, 1999). Ways of conceptualising power have tended to fall into two categories, namely "as an element of social action" and "as an aspect of social relationships" (Hugman, 1991:30).

Key writers on this subject include Lukes (1974), still widely cited today, and Foucault (e.g. 1977, 1980), particularly on discursive and disciplinary power. The work of these authors is therefore critically analysed in the following sections.

Lukes' three-dimensional view of power

Lukes' (1974) work highlights key debates in social action approaches to power. He challenges earlier agency-orientated models and proposes what he sees as a theoretically and politically radical three-dimensional conceptualisation of power. While the common core of the concept for Lukes is an agency-orientated view of 'power over', i.e. as 'A' somehow affecting 'B' in a significant way, Lukes argues that different criteria of significance are used in conceptualisations of power.

The one-dimensional view of power

Lukes critiques what he terms the one-dimensional and two-dimensional views of power. The one-dimensional ('constant-sum') view of power, proposed by Dahl and pluralists in the 1950s and 1960s, introduced the 'intuitive idea of power' i.e. that "A

has power over B to the extent that he can get B to do something that B would not otherwise do" (Lukes, 1974:11-12).

However, Lukes criticises the pluralists' emphasis on observing formal behaviour to identify power in decision-making situations, arguing that there may be less visible ways in which a system is biased towards particular groups. The one-dimensional view of power also fails to consider whether the exercise of power is actually intended, and ignores structural aspects of power (Clegg, 1989).

The two-dimensional view of power

The two-dimensional view of power proposed by Bachrach and Baratz in the 1960s highlighted the way in which individuals or groups are able to both create and reinforce obstacles to certain policy issues being aired in public via 'mobilisation of bias'. Lukes notes that the two-dimensional view of power is an advance over the one-dimensional approach in that it includes consideration of controlling political agendas.

However, he identifies the two-dimensional view as inadequate on four counts: its continuing emphasis on decision-making, implying conscious actions by individuals; its individualistic focus, which ignores the behaviour of groups and institutions; its emphasis on actual conflict as a prerequisite of power exercise; and its assumption that non decision-making power has to involve a grievance that is blocked from entering the political process.

The three-dimensional view of power

The three-dimensional view of power that Lukes therefore proposes extends these earlier approaches to understanding power as social action. It includes consideration of ways in which individual decisions, institutional practices and social forces function to keep potential issues off the political agenda. He notes that these processes may not involve observable conflict, as this may have been successfully prevented from occurring by manipulating people's views and preferences (p.23).

Luke suggests that 'latent conflict' may instead be present, defining this as "a contradiction between the interests of those exercising power and the *real interests*[37] of those they exclude" (p.24-25). He notes that this may occur even where those excluded from power are not conscious of or do not express their interests[38].

Lukes acknowledges limitations of his radical conceptualisation of power, suggesting that it may be problematic trying to justify the relevant counterfactual in relation to how people would behave were they conscious of their real interests. He also notes difficulties for researchers attempting to identify the process of power exercise in the three-dimensional approach, where the exercise of power may be unconscious rather than conscious, collective rather than individual, and may result in inaction rather than action.

Evaluating Lukes

Lukes' three-dimensional view of power highlights a number of important aspects of power relevant to people experiencing mental distress. Illich's (1977) concept of 'cultural iatrogenesis' is an example of power as defined in Lukes' third dimension, where dependency on professional care is fostered by cultural acceptance of the role of medicine (Wilkinson, 1999). It has also been suggested that Luke's third dimension of power means that professionals may be unaware that they are exercising power over service users, and may reject this idea (Hugman, 1991:33).

The three-dimensional view also has implications for policy imperatives to facilitate empowerment amongst health and social care service users. If service users are not aware of their 'real' interests, simply creating greater opportunities for dialogue and participation in decision-making on services will not be sufficient: consciousness-raising about oppression will also be necessary (Means and Smith, 1998).

---

[37] Original emphasis.

[38] In relation to the concept of interests, Lukes suggests that its varying definition is linked to different moral and political stances. A liberal viewpoint would see interests as what people actually want, linked to political preferences and participation (corresponding with the one-dimensional view of power). A reformist stance would argue that not all wants are equally weighted in a political system, and would link interests to wants or preferences in a more subtle, possibly concealed or submerged way (in line with the two-dimensional view of power). For the three-dimensional approach, Lukes identifies a radical viewpoint on interests, whereby "men's wants may themselves be a product of a system which works against their interests, and, in such cases, relates the latter to what they would want and prefer, were they able to make the choice" (p.34).

However, criticisms of Lukes' model have been made. Clegg (1989) argues that the way in which Lukes presents differing conceptions of interests is morally irreducible and not open for debate or analytical exploration. Lukes' work is also criticised for failing to resolve adequately the tension between conceptions of agency power and structural power (Clegg, 1989). While Lukes acknowledges the structural context of power exercise, his primary frame of reference remains human action and he does not therefore include adequate consideration of the social basis on which this action is occurring (Hugman, 1991:38).

Agency or structure?

Lukes' three-dimensional conceptualisation of power is essentially agency-oriented: he argues that discussion of power exercise necessarily assumes that "it is in the exerciser's... power to act differently" (p.55). However, this ignores the extent to which power exercise may result from structural, systemic factors, such as class, gender and ethnicity and associated structural divisions (Thompson, 1998). Layder (1997) suggests that while power may shift between individuals at a face-to-face level, this relationship will still be constrained by structural factors such as patriarchal domination:

> ...domination does not necessarily express the *behavioural (or action) dimension* of control over others, it expresses the prior relations that groups or individuals have with each other according to their position in relation to some scarce resource... and their ability to defend and stabilize this position... (p.171)[39]

Interaction and interplay between agency and structure is therefore important in conceptualising power relations (Hugman, 1991). Layder (1997) also makes a plea for the consideration of subjective power, defined as an individual's felt sense of being able to 'make a difference' in the world and the way in which they choose to deploy such power.

However, Clegg (1989) argues against understanding power in terms of either structure or agency, proposing that "power is best approached through a view of more or less complex organized agents engaged in more or less complex organized games" (p.20). Young (1990) similarly views power relations as processual and

[39] Original emphasis.

dynamic. Such advocates of a conceptualisation of power as relational and strategic are clearly influenced by Foucault's work on power, which - as discussed in the following section - focuses on neither subject nor agency.

Foucault's view of power relations

Foucault's post-structuralist work has been influential in recasting some of these traditional debates on the nature of power, and as such merits detailed exploration. His focus upon power results from his desire "to create a history of the different modes by which, in our culture, human beings are made subjects" (Foucault, 1983:208), and therefore entails analysing the nature of power relations involved in "the objectivizing of the subject" (p.209).

Indeed, Foucault's position on power differs dramatically from that discussed above in that he critiques the dialectical view of power, asserting that "one should not assume... a binary structure with 'dominators' on one side and 'dominated' on the other, but rather a multiform production of relations of domination" (1980:142). He also challenges the concept of power as a substance that is possessed by certain groups, arguing that "power is not something that is acquired, seized, or shared... power is exercised from innumerable points, in the interplay of nonegalitarian and mobile relations" (1998:94).

He defines such power exercise as "not simply a relationship between partners, individual or collective" (1983:219) but as "a way in which certain actions may structure the field of other possible actions" (1983:222). He therefore differs from Lukes, who views power as exercised by one agent over another, by identifying power as exercised via the effect of one action on another.

Foucault thus avoids attributing agency within his conceptualisation of power relations, identifying power as "a machine in which everyone is caught... a machine that no one owns" (1980:156). Although he states that all exercises of power are accompanied by aims and objectives, he argues that these aims are "anonymous" and "unspoken" rather than explicitly defined by individuals or groups (1998:95). Nonetheless, he does give some acknowledgement to structural differences in people's experiences of power, commenting that "everyone doesn't occupy the same

position; certain positions preponderate and permit an effect of supremacy to be produced" (1980:156).

Foucault (1998) views power as a series of multiple strategic relations, existing at the point of interaction and circulating throughout society, constantly changing rather than being statically distributed. For Foucault, "power is everywhere; not because it embraces everything, but because it comes from everywhere" (1998:93), interwoven with all other social relations.

He challenges the traditional representation of power as negative, repressive and limiting (1998:85)[40], emphasising the productive nature of power as it "induces pleasure, forms knowledge, produces discourse" (1980:119).

Another key aspect of Foucault's formulation of power relations is that "there are no relations of power without resistances" (1980:142). Resistances are viewed as the opposite of power relations and are therefore seen to function in the same way, present throughout power networks, irregular in distribution and changing over time and place (1998:96).

Power, knowledge and discourses

With regard to knowledge production, Foucault (1980) challenges hierarchical scientific discourse which has the effect of subjugating both local, 'popular' knowledges (such as those produced by 'the psychiatric patient') and historical approaches to understanding phenomena such as the asylum and the prison. He advocates "a reactivation of local knowledges... in opposition to the scientific hierarchisation of knowledges and the effects intrinsic to their power" (1980:85).

To achieve this aim, Foucault adopts a genealogical approach to analysing "local discursivities" (1980:85), defining genealogy as "a form of history which can account for the constitution of knowledges, discourses, domains of objects etc.,

---

[40] Foucault does acknowledge the prohibitive power of the state, but argues that this is only able to take hold if rooted in local "micro-relations of power" (1980:199). He also refutes the Marxist emphasis on power as primarily a means of maintaining economic relations of production and therefore class domination, arguing that "power is not primarily the maintenance and reproduction of economic relations, but is above all... the way in which relations of forces are deployed and given concrete expression" (1980:89-90).

without having to make reference to a subject" (1980:117). He therefore aims to explore how knowledge and power have historically come to be defined in particular ways under specific conditions.

Power plays a key role in his genealogical accounts in that he views power and knowledge as inextricably linked:

> ... the exercise of power itself creates and causes to emerge new objects of knowledge and accumulates new bodies of information... Knowledge and power are integrated with one another... It is not possible for power to be exercised without knowledge, it is impossible for knowledge not to engender power. (1980:51-52)

Following this line of argument, Foucault challenges the Marxist conceptualisation of ideology and corresponding quest for 'true' knowledge. Foucault argues that all knowledge involves power relations and is therefore ideological, and instead focuses his attention on "seeing historically how effects of truth are produced within discourses which in themselves are neither true nor false" (1980:118).

Foucault (1980) argues that "each society has its regime of truth... that is, the types of discourse which it accepts and makes function as true" (p.131). He views scientific knowledge as key in producing discourses of 'truth' in that "'truth' is centred on the form of scientific discourse and the institutions which produce it" (p.131). Foucault identifies power and 'truth' as always connected in that "'truth' is linked in a circular relation with systems of power which produce and sustain it, and to effects of power which it induces and which extend it" (1980:133).

Foucault (1998) also identifies close links between power relations and discourses, in that power relations make possible particular types of discourses, and such discourses are also used to support power relations by constructing the terms of debate and inquiry about objects of knowledge such as 'the criminal' or 'the sexual deviant'[41].

---

[41] Foucault explores these links between power relations and discourse via the issue of sexuality, in 'The History of Sexuality Volume One' (1998).

Just as Foucault views power-knowledge relations as always changing rather than static, so too he focuses upon the multiple, fragmentary nature of discourses, different elements of which come into play in different strategies (1998:100). As discourses are points at which power and knowledge join together, they can both reinforce and undermine power relations (1998:101).

Foucault's emphasis on the close relationship between knowledge and power, and the corresponding creation of discursive formations which shape the way in which particular groups are understood and acted upon, can be seen as very relevant in the lives of mental health service users due to the prevailing medical discourse on 'mental illness' which makes people experiencing mental distress both objects of inquiry and targets of intervention. Conversely, the discourses of recovery and self-management (e.g. Allott and Loganathan, 2002; Martyn, 2002), increasing in popularity and support within the mental health service user/survivor movement (as discussed on p.91-95), are clear examples of Foucault's 'subjugated knowledges' developing to challenge this traditional medical discourse.

Foucault and disciplinary power

Foucault's work is also concerned with mapping the historical evolution of networks of power relations in order to explain contemporary society (Hoy, 1986), focusing on the practices undertaken within specific institutions, as 'technologies of power' (Cousins and Hussain, 1984).

Therefore, while 'Discipline and Punish' (Foucault, 1977) is subtitled 'The birth of the prison', its primary concern is to explore the development of disciplinary power in modern societies. Foucault charts a shift in forms of punishment, from the use of torture and public executions in sovereign times to the modern emphasis on reform and correction via the penal system. Foucault argues that this development of disciplinary techniques via modern prisons constitutes the arrival of a more extensive form of social control, "a new 'political economy' of the power to punish" which aimed "not to punish less, but to punish better... to... insert the power to punish more deeply into the social body" (1977:81-82).

As such, Foucault suggests that a shift occurred in the subject of the power to punish, from the body in times of torture to the mind, enabling "the submission of bodies through the control of ideas" (p.102). This creation of 'docile bodies', i.e. "that may be subjected, used, transformed and improved" (p.136) is achieved via techniques and tactics used within disciplinary institutions (including prisons, schools and hospitals), such as ways of distributing individuals within spaces and ways of controlling activity.

The theme of surveillance, key to Foucault's conceptualisation of disciplinary power, is developed via exposition of Bentham's Panopticon, defined as "the diagram of a mechanism of power reduced to its ideal form" (1977:205)[42]. The Panopticon, whereby individuals within cells can be clearly observed by a supervisor at all times, is viewed by Foucault as a perfect means of exercising disciplinary power without the use of force by giving "power of mind over mind" (1977:206) to make residents of the cells believe that they are always under observation even when this may not be the case.

As Foucault views this model as applicable to all situations involving "a multiplicity of individuals on whom a task or a particular form of behaviour must be imposed" (1977:205), he argues that its principles have spread from institutions to create a disciplinary, 'carceral' society based upon "a generalized surveillance" (1977:209).

Foucault therefore identifies disciplinary power as an anonymous, relational form of power, operating via a network of "hierarchized, continuous and functional surveillance" (1977:176). The 'medical gaze' about which Foucault (1980, 1989) writes, institutionalised in hospitals via the central system of observation of bodies, is an example of an instrument of such disciplinary power, as is normalising judgement. He highlights the way in which disciplines punish departures from 'correct' behaviour with humiliations, deprivations and physical punishment, which can be seen as relevant to practice within psychiatric institutions (see p.110 and 112).

---

[42] The architectural structure of the Panopticon consists of a peripheral annular building, divided into cells, with a central tower. The tower has windows opening on to the inner side of the ring-shaped building, and the cells in this building each have two windows, one in line with the tower's corresponding window and one on the outside of the cell to allow light to cross the cell. In this way, individuals in the cells can be clearly seen by the supervisor observing from the tower, and are thereby trapped by their visibility.

Foucault (1977) argues that these two instruments of disciplinary power, hierarchical observation and normalising judgement, combine within the examination, for example the medical examination, to powerful effect. The examination enables the invisible exercise of disciplinary power by making its subjects feel constantly visible (p.187). The examination also involves the disciplinary function of classification, which both objectifies and individualises people and compares them to the 'normal' distribution of a given population. In this way, disciplinary power uses "procedures of individualization to mark exclusion" (p.199), as undertaken via psychiatric classification for example (as discussed on p.15-16).

The key feature of such a carceral society is control via continuous surveillance, internalised by individuals such that they undertake self-monitoring and regulate their own behaviour:

> ...the system of surveillance... involves very little expense... Just a gaze. An inspecting gaze... which each individual under its weight will end by interiorising to the point that he is his own overseer, each individual thus exercising this surveillance over, and against, himself. (1980:155)

This is a significant issue in the lives of mental health service users, in that the perceived (and real) fear of surveillance may lead to constant concern about how their behaviour is interpreted and potentially 'punished' via sanctions, and their corresponding monitoring and management of their own behaviour according to socially defined 'norms'.

Evaluating Foucault

Foucault's approach to power, while influential, has been heavily criticised. A primary criticism is Foucault's lack of consideration of power as an aspect of human agency (Layder, 1997; McGowen, 1994). For example, the way in which Foucault (1980) describes the operation of strategies which have powerful effects and yet cannot be attributed to any individuals' actions or intentions is questionable (Merquior, 1991:112-113)[43].

[43] Indeed, this lack of consideration of agency was poorly defended by Foucault in an interview reproduced in 'Power/Knowledge' (1980:202-207).

Foucault is also criticised for failing to consider adequately the institutional basis of power, for example in relation to the development and implementation of disciplinary practices and institutional regimes (Driver, 1994). This lack of consideration of structural elements, presumably due to Foucault's dislike of state-centred conceptualisations of power, leaves Foucault's work unlocated in broader social structures (Layder, 1997). Porter (1996) uses the example of British soldiers in Northern Ireland stopping and searching local people to argue that while such micro-social interactions involve the exercise of power, they can only be fully understood in the context of the structural conditions which make such power exercise possible.

Foucault's assertion that power should be understood as primarily creative and productive can also be challenged to the extent that repressive, traditional forms of power may still exist alongside the modern, creative forms of power he describes (Layder, 1997:14).

Foucault's determinism, "in which discourses are represented as subjugating human agency with little scope for resistance or acknowledgement of the 'lived experience' of the body" (Lupton, 1997:101) is also subject to criticism. His conception of 'docile bodies', for example, appears at odds with his assertion that resistance is possible wherever power relations are operating.

Nonetheless, his approach to power is helpful for this dissertation in highlighting the close relationship between knowledge and power, and the corresponding creation of discursive formations which shape the way in which particular groups are understood and acted upon, of great relevance in the lives of mental health service users (see p.56).

Foucault's exposition of disciplinary power in modern society also has resonance in relation to mental health service users. The instruments of disciplinary power Foucault identifies, namely hierarchical observation, normalising judgement and the examination, are familiar themes in the lives of mental health service users, for example in relation to the psychiatric diagnostic systems which are largely based on

socially-defined behavioural norms (see p.15), and the continuous observation and assessment experienced by people using inpatient psychiatric facilities.

Foucault's idea of constant surveillance extending throughout society and people's corresponding self-monitoring of behaviour is a powerful way of conceptualising the experiences of people in mental distress both of inpatient psychiatric 'care' and of life 'in the community'. However, Foucault's idea of surveillance can also be interpreted more positively in relation to the mental health user/survivor movement's self-management approach (see p.94).

It has been suggested that "although Foucault's notion of power is nontraditional, it is not incommensurable with more traditional social theory" (Hoy, 1986:123-124), and indeed Layder (1997) views Foucault's work as exposing one aspect of power's many forms. A view of power which acknowledges the structural aspects of power and oppression, yet also accounts for dynamic and fluid power relations between individuals and groups at different points in time, often linked to the production and reproduction of discourses, is therefore advocated in this dissertation. In this way, while people might be defined as powerless in a specific situation at a particular time, the view of particular groups of people as forever powerless is avoided and the possibility for resistance is highlighted (Humphries, 1994).

Such a view accords with Layder's (1997) comprehensive theory of power, whereby power is viewed as a multi-dimensional process, forming part of human agency, individuals' psychological make-up, discursive practices, and society's structural parameters (p.15).

The next section turns to the specific arena of professional power, taking into account the above discussions of the nature of oppression and power. Conceptualisations of professional power are of key relevance in this dissertation as professionals play such significant roles in the lives of many mental health service users (whether by choice or through enforced contact).

Professionalisation and professional power

It is important to consider the nature of power involved in relationships between professionals and people experiencing mental distress[44], not least because service users are often particularly vulnerable at the point at which they come into contact with professionals (Clough, 1990; Meerabeu and Abbott, 1998) and the potential for misuse of professional power is therefore significant (Thompson, 1998)[45].

Similar to the contested nature of power discussed above, differing conceptualisations of professional power exist in line with writers' favoured theoretical frameworks (Hart, 1985), and these are explored in the following section.

Professions and professional power

A range of theoretical frameworks has been applied to the professions by social theorists. The neo-Durkheimian approach emphasises the altruistic and community-focused nature of professions and their important social function (Turner, 1987). However, this functionalist approach has been criticised for its lack of consideration of power issues (Johnson, 1972), including struggles for control of occupational activities (Saks, 1983).

Writers within the neo-Weberian framework adopt a more critical approach, viewing professions as self-interested institutional forms of occupational control (Freidson, 1988; Illich, 1977; Johnson, 1972). Those in the Weberian tradition emphasise professional dominance, with professional power being exercised over service users, new recruits to the profession, and over other occupational groups (Pilgrim and Rogers, 1993). Thus a relatively unidirectional view of professional power is implied by the neo-Weberian framework.

---

[44] An extensive literature also exists on the power of health and social care professions in relation to each other (e.g. Morrall, 1998; Rogers and Pilgrim, 1996; Walby et al, 1994; Witz, 1994), but as the focus of this dissertation is on the experiences of mental health service users rather than the experiences of professional groups, this literature is not included here.

[45] Extensive debate also occurs within the academic and practice literature regarding the extent to which 'caring' occupations such as social work and nursing can claim to be 'professions', with many authors concluding that they are 'semi-professions' (although such conclusions tend to be drawn by measuring them against 'traits' developed from the more established professions of medicine and law) (Abbott and Wallace, 1990; Morrall, 1998). However, for the purposes of this dissertation, the key issue is not whether nursing and social work are professions but the meaning of their claims to professional status in terms of power relations with service users, and the debate about their professional status is not therefore explored here.

The defining characteristic of a profession is seen by Illich (1977) as having the authority and legitimacy to define a person as a client, to determine their needs, and to give a prescription for those needs. Illich argues that this emphasis on needs that only professionals can fulfil is ultimately disabling, engendering helplessness amongst people and stopping them from carrying out tasks which they would previously have done for themselves (p.28).

Poststructuralists have a different starting point with regard to the nature of professions, focusing upon their 'discursive practices' (Morrall, 1998:12-13) and corresponding power relations (Macdonald, 1995:178-179). Foucault's concept of surveillance via 'the disciplinary society' has resonance with regard to health and social care professionals, many of whom are either explicitly or implicitly involved in surveillance of service users, at the same time as being subject to disciplinary practices themselves (Thompson, 1998). Surveillance of service users is often linked to normalising judgements, which again can be seen as an element of professional power. Indeed, psychiatric discourse has been identified as fundamentally normalising (Rogers and Pilgrim, 2003:181).

However, the criticisms of Foucault's work highlighted above, particularly the lack of a clear conceptualisation of human agency, are also relevant with regard to professional power, in that "in the poststructuralist account there is a failure to endorse the notion of self-conscious collective activity of professionals, to advance their own interests" (Pilgrim and Rogers, 1993:86).

Therefore, similar to debates rehearsed earlier in this chapter, professional power can be seen to involve elements of both structure and agency, and complex interactions between power, knowledge and discourse.

Forms of professional power

Wilding (1982) suggests that while literature exists on particular professions' power, there has been a lack of analysis of the general way in which what he terms 'the welfare professions' (namely health and social care professions) exercise power in society. He therefore uses a neo-Weberian framework to explore the nature of power

within the welfare professions[46], and the legitimising basis of this power (and as such tends to suggest unidirectional 'power over' relations between professionals and service users). These typologies include the major themes covered by literature in this area, such as Hugman's (1991) work on the power of 'caring professions' (including nursing and social work), and will therefore be used to structure the following sections.

Wilding identifies five different forms of professional power, namely "power in policy making and administration; power to define needs and problems; power in resource allocation; power over people; and power to control the area of work" (1982:19).

Power in policy-making and administration

Wilding suggests that professional power in policy-making and administration has three implications for welfare services, namely that: decisions may be made in professionals' rather than the public's best interests; services may be organised according to professional need and areas of interest rather than service user need; and decision-making within the professions may be dominated by certain groups with greater status and seniority[47].

Power to define needs and problems

The second form of professional power identified by Wilding, which underpins the power to influence policy, is professionals' power to define people's needs and problems via a combination of "decision making, agenda setting and normative power" (Clarke and Newman, 1997:63).

The corresponding construction of 'the service user' or 'the patient' as an object for assessment and intervention, rather than as a subject to be involved in making decisions and defining their own needs, leads to their marginalisation within both the organisation and practice of professions (Hugman, 1991). Wilding argues that

---

[46] Wilding acknowledges that his work draws heavily upon evidence and theorising on the medical profession as most has been written about this particular occupational group, but suggests that "the medical profession should be seen as an example of a more general characteristic of welfare states" (1982:19).

[47] Wilding cites the example of the dominance in the NHS of hospital medicine, with its powerful consultants and specialised technology, over primary care (although this is now shifting with the current government's increasing emphasis on primary care as the driver of health care provision) (Department of Health, 1997).

professional definitions of need tend to be imposed upon people rather than agreed, thereby disregarding an individual's own understanding of their situation and experience. He suggests that this approach has implications not only for the treatment the individual service user receives, but also for the broader configuration of services (p.34).

Wilding also highlights that such definitional power encourages problems to be conceptualised within the boundaries of a particular professional body of knowledge e.g. viewing alcoholism as disease, and grief as depression. He argues that such narrow vision can lead to a lack of consideration of political and structural issues.

The use of professionally-defined language can also be seen as a means of reproducing power in the professional/service user relationship (Hugman, 1991). Language use involving power dynamics includes the use of professional jargon, stereotypes, stigmatising language, and depersonalising language (such as 'the disabled') (Braye and Preston-Shoot, 1995; Thompson, 1998).

Power in resource allocation

Power in resource allocation is seen by Wilding as operating at a local and central government planning level, an organisational level, and at the level of individual professional/service user interactions, where professionals make decisions about the use of both material resources and their own time.

Lipsky's (1980) seminal work on 'street-level bureaucrats'[48], defined as "public service workers who interact directly with citizens in the course of their jobs, and who have substantial discretion in the execution of their work", (p.3) has value for this discussion in highlighting their considerable power over service users as they make resource decisions which significantly affect people's lives, for example in allocating or withholding benefits.

---

[48] Lipsky includes within his definition of street-level bureaucrats health and social care professionals such as doctors, nurses and social workers.

Wilding highlights four effects of this professional power in resource allocation: it enables professionals to have significant control over how services are actually run, irrespective of policy guidelines and priorities; it allows professionals to operate services for their convenience rather than for that of service users; it undermines generalised planning and management of services as individual professionals have considerable discretion in making decisions; and it masks the political nature of policy decision-making. In this way, "what should be identified as a political process becomes regarded as a matter of technical judgement" (Hugman, 1991:125).

Power over individuals

While the first three forms of professional power clearly affect service users in terms of the kinds of services received and by whom, Wilding identifies direct 'power over' people as a fourth form of professional power. He suggests that this power is both implicit, for example GPs' power to remove patients from their 'list' if they no longer wish to treat them, and explicit, for example psychiatrists' and approved social workers' legally mandated powers to compulsorily commit people to psychiatric inpatient facilities. Direct control by professionals over many aspects of peoples' daily lives and identities can be seen to operate in institutions such as psychiatric hospitals and residential homes (Hugman, 1991:119).

Street-level bureaucrats exercise power by routinely controlling service users in a variety of ways, for example via: the setting, content and timing of their interactions with service users; their tendency to isolate service users from one another, thereby encouraging them to individualise their situation; and their presentation of decisions and resource allocations as being in the service users' best interests at all times (Hudson, 1993:388).

It is clear from earlier discussions of power in this chapter, however, that not all 'power over' service users can be conceptualised in a simplistic unidirectional way, independent of broader considerations. All interactions between professionals and service users are likely to be mediated by the structural context of other social divisions, such as class, gender and ethnicity (Hugman, 1991:16-17). Service users may be able to resist or challenge this exercise of professional power over them (see p.73). Equally, professionals can feel powerless relative to others (for example

managers, or other professions) despite appearing powerful to service users (Fook, 2002).

It is clearly important to acknowledge that the exercise of professional power can be productive as well as repressive (Gomm, 1993). Such professional 'power to' can be exercised in a way which benefits rather than disempowers service users, for example by securing resources for service users (Payne, 1979) or by ensuring that their rights are upheld in decision-making processes (Dalrymple and Burke, 1995).

Power to control area of work

Wilding's fifth form of professional power is control of work area via self-regulation, and via "the ability of a profession successfully to define itself as the key group in the delivery of a particular service" (p.57). He observes that the medical profession has been very successful both in convincing the public that they are a vital component in securing the nation's health and in identifying themselves as a key group involved in providing health services.

Finally, Wilding suggests that professionals succeed in maintaining control over their work in their individual interactions with service users, in terms of the way in which they meet with and work with service users.

The basis of professional power

Wilding (1982) also gives five possible explanations as to how and why welfare professions have managed to secure and legitimate such power, outlined in Figure 5 (p.67).

Figure 5: Five bases of professional power

1) Alliance between professions and the state

- This alliance results from their mutually dependent relationship and has granted welfare professions either implicitly or explicitly all of their forms of power.

2) Nature of state welfare

- The government's involvement in welfare programmes and services gives power to those professions, as the government depends on the professions to act as its agents in carrying out its policy commitments.

3) Professional expertise and knowledge

- Professional expertise and knowledge, and the authority and legitimacy which derive from this expertise, provide another basis for professional power. Professions' construction of particular bodies of knowledge and associated discourses have traditionally defined the way issues are viewed in society.

4) Professional guarantees regarding use of power

- Guarantees are offered by professionals regarding the use of their powers and freedoms, such as their claim to trustworthiness, their service ideal, and colleague control of the profession.

5) Public acceptance and support for professionals

- Such public acceptance results partly from the government's endorsement of professions, and partly from people's belief in the importance of professionals' work, in professions' expert knowledge and in professionals' service orientation.

(Source: Wilding, 1982:65-82)

Wilding's work has been criticised for oversimplifying the complexities of power relations amongst different professions (for example between doctors and social workers during a sectioning procedure) in the process of attempting to define common elements of power (Hugman, 1991:5). Nonetheless, as stated earlier, a focus of this dissertation is upon the power of professionals relative to service users, rather than relative to other professionals. Wilding's work, as one of the most comprehensive attempts to outline the differing forms and bases of this power amongst health and social care professions, is therefore of value in this dissertation.

Professions in the lives of mental health service users

One of the key features of professional power in relation to mental health service users is direct 'power over' people in the form of "delegated coercive power" (Rogers and Pilgrim, 2003:175) to order the involuntary detention and treatment of people experiencing mental distress. As such, mental health professionals can be viewed as agents of social control, with regard to both coercive and voluntary attempts to 'cure' behaviour considered 'deviant' in terms of socially-defined norms. Tensions are therefore apparent for mental health professionals, who are expected to both support people in distress and to control them either for 'their own good' or for the public good (Howell and Norman, 2000).

Specific features of individual occupational groups are briefly considered in the following sections to highlight power relations involved and to contextualise empirical evidence presented in later chapters.

Medicine and psychiatry

As highlighted above, medicine is a profession whose members exercise considerable power both individually and collectively. This power is based upon state-mandated legal powers, a high degree of technical expertise, and strong public acceptance of doctors' authority. Harrison et al (1992:19) argue that cultural factors reinforce the medical profession's power, with high social status, respect and accompanying deference accorded to doctors both by other health care workers such as nurses and by the general public.

Lukes' three-dimensional view of power can contribute to understanding the medical profession's ability to influence the health care agenda by using their culturally reinforced status to manipulate people's values and preferences, and may help to explain why increased managerialism within the NHS has been said to have failed to seriously undermine the medical hegemony (Hunter, 1994)[49].

---

[49] Another contributory factor in doctors' continuing dominance may be that the medical profession has succeeded in taking on managerial 'clinical governance' roles while retaining a strong element of 'clinical autonomy', thereby bestowing professional legitimacy on managerial decisions about health care rationing (Exworthy and Halford, 1999).

As discussed above, social divisions can often reinforce the power imbalance between professionals and service users, and are particularly acute in relation to class and ethnic differences between doctors and patients (Johnstone, 2000:132).

Although psychiatry's dominance may have become "much more tenuous" (Rogers and Pilgrim, 1996:100) in recent years[50], psychiatrists still have the power to apply stigmatising diagnostic labels, prescribe powerful physical treatment, and detain and treat people against their will (Rogers and Pilgrim, 2003) and therefore remain powerful professionals in the lives of mental health service users (Johnstone, 2000). Indeed, it has been argued that technological, pharmaceutical and biogenetic developments may be enhancing the power of medicine in contemporary society (Morrall, 1998).

General practitioners (GPs) also play an important role in the lives of many mental health service users, both as gatekeepers to specialist psychiatric services and as the primary source of support for most people experiencing mental distress in the community, and are therefore in a relatively powerful position (Johnstone, 2000).

Mental health nursing

It has been argued that the 'caring professions' of both nursing and social work have always been subject to the power of the state and of more established professions (Hugman, 1991; Godin, 1996). Indeed, while mental health nurse training now emphasises a more client-centred, socially located approach to working with service users, tension exists with what nurses are expected to do in line with psychiatry's social control function (for example, forcing people to take medication, and applying physical restraints in inpatient facilities) (Morrall,1998:121).

This tension can be seen in the role of the community psychiatric nurse (CPN), which involves both productive power or 'power to', and 'power over' service users, including: "formal and informal assessment of a client's mental health; the implementation of preventative, educative, and specific therapy programmes;

---

[50] This weakening of psychiatry's position is seen to result from shifts which include the development of nurse-managed community mental health teams and corresponding emphasis on multi-disciplinary working (Rogers and Pilgrim, 1996).

supportive visits; providing a consultative service to other health-related and voluntary agencies; the provision of physical care, as well as the giving of injections" (Morrall, 1998:15).

However, the introduction of the care programme approach and supervised discharge orders has led to CPNs taking on key worker roles within that legislation and arguably becoming more explicit agents of social control (Morrall, 1998). Indeed, with increasing government emphasis on public safety and control in relation to mental health services, it is likely that this overt policing role by mental health nurses will continue to be emphasised despite concerns expressed by mental health nurses about the implications of this role for their attempts at partnership working with service users (Howell and Norman, 2000).

Social services workers

Social work has a strong social justice value base (Fook, 2002), acknowledging and challenging social inequalities (Hugman, 1998) and working with society's most disadvantaged groups (Harris, 1997). Nonetheless, similar to mental health nursing, the combination of both care and control functions within social work (Dominelli, 2002:28) mean that power relations are a key element of social workers' roles (Payne, 1979) (for example in approved social workers' legally mandated authority over mental health service users) (Harris, 1997).

The likelihood that such intervention by social services is unwelcome for people experiencing mental distress, and may for example have been instigated by carers or families 'troubled' by someone's perceived 'abnormal' behaviour, emphasises the powerful nature of the social worker's social control role (Clough, 1990)[51].

As a mediated profession, the nature of social work and its interactions with service users involves state-defined power relations (Harris, 1997). Social work's location within local authorities also renders it subject to economic and political imperatives,

[51] It is acknowledged that while social workers are relatively powerful in their interactions with service users (Harris, 1997), and are likely to be perceived as such by service users (Clough, 1990), they may feel powerless with regard to the organisational structure within which they are expected to function (Fook, 2002) and caught between competing interests (Clough, 1990).

which may not necessarily correspond with service users' interests (Clough, 1990; Dominelli, 2002).

As a result of the NHS and community care reforms, a key element of many social workers' roles is that of assessment and care management. As such, Alaszewski (1995) identifies an enhanced yet constrained role for social workers in that "care managers... have increased flexibility to manage packages of resources but... have to account for their use of these resources" (p.72). The power to determine resource allocation has been highlighted above as an important form of professional power (Wilding, 1982).

Acknowledging the potentially oppressive nature of social work interventions with service users, many social work authors advocate anti-oppressive or anti-discriminatory models of practice (Hugman, 1998) which involve "recognizing power imbalances and working towards the promotion of change to redress the balance of power" (Dalrymple and Burke, 1995)[52].

Community care workers are another group of social services staff who have considerable contact with people experiencing mental distress, tasked with dealing with people's social needs and offering practical support to enable independent living in the community (Johnstone, 2000:137). These workers are likely to be subject to resource constraints and assessment issues in a similar way to social workers.

Voluntary sector workers

Mental health service users also access a range of voluntary sector provision, which has traditionally been characterised as "more flexible and innovative and less institutionalised, working in partnership with service users" (Johnstone, 2000:141). Research suggests that "service users particularly appreciate the informality, support, sense of equality and opportunity to contribute that characterises voluntary agencies" (Johnstone, 2000:142).

---

[52] These models of social work practice will be further discussed in Chapter Three in relation to professional practice and empowerment.

Indeed, with regard to service user experiences of mental health professions, it has been argued that "paradoxically, mental health staff are likely to be found helpful in inverse relation to their status, power, salary and length of training, with voluntary workers getting the most favourable rating of all" (Johnstone, 2000:144).

Increasingly, however, voluntary sector organisations are entering into contracts with statutory services to provide services such as day care, within the 'mixed economy' of community care (Batsleer, 1995). This shift is creating new power relations, particularly as such organisations may become financially dependent on statutory services. It has been argued that voluntary organisations' objectives and ways of working may be distorted by contract arrangements which emphasise government priorities (Clarke and Newman, 1997).

Shifting professional power relations?

In the 1980s, the British Conservative government moved to increase the effectiveness and accountability of welfare professionals via "the pincer-like disciplining mechanisms of increased political control, tighter managerial control, and the empowering of consumers" (Foster and Wilding, 2000:146). Such developments were continued by the subsequent Labour government and its emphasis on 'modernising' health and social services (Means et al, 2003), with an ongoing focus on audit, governance (Department of Health, 1997) and user involvement in health and social care service planning (explored on p.132-133).

As a consequence of this state-instigated erosion of professional power (Morrall, 1998), it can be argued that professions now occupy a less central role in the policy-making process, are subject to a greater level of inspection, audit, management and financial accountability[53], and are more challenged by service users with regard to quality of care, choice of services, and the view of professionals as 'experts' (Fook, 2002).

Resistance to professional power from service users can be identified on both individual and collective levels. Individually, service users can and do challenge

[53] More detail on the 'new public management' operating in public services since the 1980s can be found in Clarke (1998), Clarke and Newman (1997), Exworthy and Halford (1999) and Flynn (1999).

professional interpretations of their situation and desired solutions. While such challenges may be beneficial in forcing professionals to confront the coercive power involved in their role, and may thereby challenge the professionals' legitimacy to exercise power in this way, they may also lead to professional attempts to discredit individuals' characters (Hugman, 1991:135).

Collective resistance to professional power may therefore be more effective in achieving shifts in power relations. The growth of both self-help and campaigning groups of service users throughout the UK, many of whom reject their objectification as 'patients' or 'clients' (Hugman, 1991), can be seen as a challenge to professional power exercised through knowledge production and practice. Such a challenge is exemplified by mental health service users' production of alternative discourses both of mental health, for example with regard to hearing voices (Coleman, 1999a), and of 'treatment' for mental distress, for example via recovery and self-management approaches (Martyn, 2002; Ralph, 2000)[54].

Nonetheless, it should be acknowledged that many professionals are committed to facilitating the empowerment of service users, for example by supporting service users to exercise control and access decision-making forums, and by working within anti-oppressive practice models (e.g. Dominelli, 2002).

Conclusion

Keating's (1997) model of oppression, which suggests that processes of stratification, via domination and differentiation, lead to and reproduce psychological, socio-cultural and socio-political dimensions of oppression at a range of levels, offers a wide-ranging approach to understanding the complex nature of oppression, including the interaction between agency and structure.

Similarly, common themes of oppression relevant to the experiences of mental health service users can be identified, including: the social control function of dominant ideas; power relations; the use of coercive activities; restriction of personal freedom

---

[54] These challenges to professional dominance are explored in more depth in Chapter Four of this dissertation in the context of service user strategies for empowerment.

and denial of rights; social exclusion; the creation of (supposedly biologically-based) hierarchies to preserve dominant interests; prejudice and stereotypes; the interplay between dimensions of oppression; and the possibility of resistance to oppression. Keating's work is therefore proposed together with these themes as a helpful framework for exploring the nature of oppression in the lives of mental health service users, as undertaken in Chapters Four and Seven of this dissertation.

Like oppression, power relations are present both in interactions between individuals and in structures and institutions which systematically exercise power over particular groups in society, an assertion which is substantiated in relation to mental health service users by empirical evidence in later chapters.

Foucault's approach to power is considered to be of value in this dissertation in highlighting the complexity of power relations, the relationship between power, knowledge and discourse, and the operation of disciplinary power in society. However, limitations to Foucault's conceptualisation of power for understanding the many ways in which power may be experienced by mental health service users do exist. Foucault's lack of clarity regarding the role of agency is hard to reconcile with the numerous examples of discrimination experienced in one-to-one situations by mental health service users (as described in Chapter Four).

Similarly, Foucault's underplaying of structural elements in the exercise of power is difficult to apply to mental health service users' experiences of power relations, for example in relation to mental health services, many of which clearly result from institutionalised structural power. Foucault's view of power as primarily productive is also countered by the experience of many mental health service users of repressive power such as that exercised by mental health professionals with legally-mandated coercive powers.

Nonetheless, Foucault's exploration of the links between power, knowledge and discourse, and the way in which certain discursive formations achieve dominance at particular times such that humans are understood and acted upon in a particular manner, will be used in this dissertation to highlight the impact upon mental health service users of prevailing medical discourses (for example on p.223-224), and the

production of alternative discourses of mental distress by the mental health user/survivor movement (see p.130).

Foucault's conceptualisation of disciplinary power resulting in a normalising 'carceral society' characterised by institutions of supervision and surveillance also has considerable resonance with mental health service users' experiences (see p.59), and is therefore drawn upon in this dissertation to analyse experiences of people in mental distress (for example on p.126 and p.230). Foucault's idea of surveillance can, nonetheless, also be applied in a more positive way to the mental health user/survivor movement's self-management approach (see p.94), with its emphasis on the development of skills and strategies by mental health service users to manage and minimise their distress in ways which enable them to retain control of their lives. These elements of Foucault's work will therefore be used to inform analysis of mental health service users' experiences in this dissertation, combined with a structural approach to understanding power in acknowledgement of the structural oppression experienced by people in mental distress and the structural constraints on their capacity to exercise power and control in their lives.

It is clear from exploration in this chapter that professional power derives in part from the state's legitimation of professionals' authority in the form of occupational autonomy and control. Such power can be seen to operate extensively within the medical profession, and within the mental health professions with their legal authority to both admit and treat people against their will. In addition, Foucault's work helps to illuminate other elements of professional power relations, including the role of knowledge and discourse in the medical profession's disciplinary power over the body, the productive use of power by professionals in support of service users, the potential for shifting power relations, and the possibility of service user resistance to this professional power, as will be explored in later chapters.

Challenges to professional dominance can be seen to result from state-led modernising reforms, the new public managerialism, and service users themselves. Although for the time being medicine seems to be continuing its (albeit weakened) dominance and control over health and illness, and therefore over related mental health occupations, strong resistance to this professional power is being voiced by

mental health service users both via statutory service channels and via independent or voluntary sector campaigning and advocacy groups. These challenges will be further explored in Chapter Four.

The next chapter will critically analyse literature on empowerment, recovery, involvement and participation, as key concepts relating to the aims of this doctoral research.

Chapter Three: Conceptualising empowerment, recovery, involvement and participation

Introduction

This chapter aims to clarify the meaning of the much used term 'empowerment' via an exploration of professional, academic and service user literature published in the English language. A range of competing ideologies underpins definitions of empowerment, and the need to explicitly define theories of power on which these definitions are based is therefore suggested.

Consumerist and liberational models of empowerment and the view of empowerment as professional practice are critically explored. Issues in conceptualising empowerment, including levels at which it operates, processes involved, and measuring empowerment, are also discussed.

The recovery approach, as an emerging mental health paradigm driven by people with experience of mental distress, is discussed due to its close relationship with empowerment. The terms 'involvement', 'participation' and 'empowerment' are often used interchangeably. The meanings of participation and involvement are therefore reviewed in order to identify ways in which they might relate to empowerment.

Defining empowerment

Empowerment as a concept has its roots in a diverse range of traditions including civil rights, anti-racist and women's movements, self-help and mutual aid, the work of Freire, and community psychology (Adams, 1996; Forrest, 2000; Graham, 2002; Rappaport, 1987). Perhaps because of these diverse origins (Evans, 1992), empowerment is a contested concept (Parsloe, 1996), holding varying meanings with different underpinning assumptions and ideologies (Braye, 2000; Pease, 2002) and differing emphases on personal and political dimensions (McLean, 1995).

There is growing interest in empowerment in the fields of health and social care. However, it has been argued that empowerment, used as a fashionable word by both politicians and professionals (Humphries, 1994), is in danger of becoming "abused and devalued" (Dalrymple and Burke, 1995). This may be partly due to the lack of theoretical underpinning to much empowerment discourse (Rissel, 1994), a result of its development "through specific practical projects, not rhetoric" (Morgan, 1993:189). Nonetheless, theory can help to illuminate different dimensions of empowerment and therefore contribute to the development of empowering initiatives.

Competing discourses of empowerment include the consumerist model, focused on giving people choice within professionally defined services, and the liberational model, concerned with changing the position of oppressed groups in society (Croft and Beresford, 1995; Means and Smith, 1998). There is also a conceptualisation of "empowerment as professional practice" (Baistow, 1994:34) that defines empowerment both as a process of people gaining control over their lives, and as methods used by professionals to achieve this (Grace, 1991; Thomas and Pierson, 1995). This duality of definition reflects debates about theories of power underpinning conceptualisations of empowerment.

Power and empowerment

A theoretically coherent definition of empowerment should be based upon an explicit theory of power (Atkinson and Cope, 1997; Ristock and Pennell, 1996), and definitions of empowerment are likely to vary according to the underpinning theory of power (Pease, 2002).

Power imbalances between service users and professionals and their organisations have been widely documented (Gradwell, 1993; Jack, 1995). However, there is disagreement about whether an increase in service users' power necessarily entails a decrease in that of professionals as a 'constant-sum', finite conceptualisation of power would suggest, or an overall increase in power as implied by a 'variable sum' conceptualisation (Barnes and Bowl, 2001; Wilkinson, 1999). It can be argued that power is only won by certain groups at the expense of others (Rissel, 1994; Ungerson, 1997). Nonetheless, if power as defined as relational, there can be an overall gain in

power if service users become empowered (Barnes and Walker, 1996; Beresford and Croft, 1993).

It is also asserted that "conceptualizing a powerful-powerless dichotomy may in itself disempower... clients" (Pease, 2002:138), as this ignores the dynamic nature of power relations (Boje and Rosile, 2001; Fook, 2002) and the possibility that service users are exercising forms of power in their interactions with professionals.

Lukes' (1974) three-dimensional view of power highlights different levels of power relations (see p.49-51) and therefore several ways in which empowerment processes might operate. These include: rebalancing power in one-to-one situations, for example assessment for services; exposing ways in which systems are biased towards particular groups, for example racism within the mental health system (Browne, 1996); and challenging ways in which potential issues are kept off the political agenda, via individual decisions, institutional practices or social forces.

Foucault's (1998) multi-layered view of power suggests that approaches to empowerment will need to consider the complex ways in which power is exercised in any given situation (Fook, 2002). Foucault (1980) also argues that power relations always involve associated discourses (see p.55-56). Empowerment could then include redefining the prevailing discourse or producing an alternative discourse (Ward, 2000), as has been attempted for example by some mental health users/survivors by developing social models of mental distress (highlighted on p.34).

The conceptualisation of power advocated in this dissertation is one which acknowledges the structural aspects of power and oppression, yet also accounts for dynamic power relations between individuals at different points in time (see p.60). This implies that empowerment is likely to involve processes at both an individual and structural level, and to be a locally sensitive concept. Such a stance also suggests that while people might be defined as powerless at a particular point in time, groups of people are not forever powerless due to the possibility of resistance.

Consideration of the complexities of theorising power highlights the inadequacy of much empowerment literature in that many authors fail to explicitly detail an

underpinning theory of power (Boje and Rosile, 2001; Wolff, 1993). Different conceptualisations of power can be seen in the models of empowerment discussed below, broadly defined as consumerist, liberational, and 'empowerment as professional practice'.

Models of empowerment: the consumerist model

An example of a consumerist definition of empowerment, which demonstrates its limited and professionally defined nature, is given by Donlan (1993):

> Empowered living... is characterised by an enhanced ability... to discern priorities, to participate assertively, and to reach for true compromise... (p.31-32)

Similarly, Higgins' (1997) study of stakeholder perceptions of user involvement in community care found that service providers narrowly conceptualised empowerment in terms of "developing greater individual choice through market mechanisms" (p.45)[55]. This view of empowerment is clearly focused on services in both its terminology and its scope, viewing the empowered service user as a 'discerning' consumer able to make pragmatic choices from services on offer (Smale et al, 1993).

A consumerist approach to empowerment was clear in the NHS and Community Care Act 1990 and resultant policy changes (Braye, 2000; Means and Smith, 1998), reflecting the broader emphasis on the individual as 'consumer citizen' encouraged by British Conservative governments during the 1980s and 1990s (Hart et al, 1997). The current British Labour government and related statutory organisations generally continue to view empowerment in consumerist terms (Atkinson, 1999), as can be seen, for example, in the NHS Plan's emphasis on 'empowerment' of 'patients' via information provision and redress (Department of Health, 2000a).

The service-defined consumerist approach has a narrow, individualised focus on people's ability to make choices within predetermined service systems (McLean, 1995). This view of empowerment is problematic, ignoring service users' own perceptions of more fundamental changes required in their lives. Many people would

---

[55] Taylor et al (1992) further distinguish between market approaches to consumer empowerment, which give consumers the option to 'exit' from a service if they are not happy, and democratic approaches, which emphasise giving consumers a 'voice' within services.

not choose to define their empowerment in relation to services based on inappropriate conceptualisations of their distress:

> As one man with experience of psychiatric services said, 'People who use mental health services are no more consumers of them than wood lice are of Rentokil' (Croft and Beresford, 1993:xv)

The individualistic emphasis also deflects attention from oppressive social structures and power relations in society (Adams, 1998; Pease, 2002). Such issues are addressed by the liberational model of empowerment, described below.

The liberational model of empowerment

In contrast to individualised service-focused definitions, the liberational model of empowerment has been defined thus:

> Empowerment is... first a process of personal growth and development which enables people not only to assert their personal needs and to influence the way in which they are met, but also to participate as citizens within a community... change has to take place within social systems as well as within individuals and within services. (Barnes, 1997b:71)

The liberational model therefore implies a more political context by highlighting the need to challenge oppression, exclusion and power imbalances in society (Graham, 2002; Ramcharan and Borland, 1997). By focusing on people's lives and experiences as a whole, the liberational model of empowerment moves beyond a narrow service focus and is therefore more congruent with the way people view their lives[56].

This model also suggests that empowerment should be considered beyond individual, personal levels to encompass the way in which social systems and structures either facilitate or inhibit empowerment (Anderson, 1996), acknowledging that oppression operates at both individual and structural levels.

Nelson et al (2001) emphasise that people experiencing mental distress are an oppressed group, and as such argue that "it is hard to imagine a process of empowerment occurring in the absence of improvement in the material conditions of life of (mental health) consumers" (p.126).

---

[56] It is acknowledged that services may nonetheless be a primary consideration in some mental health service users' lives due to their often extended contact with services.

Empowerment as professional practice

The above models are conceptually distinct, with the consumerist model focusing upon individual choice within 'the market of services', while the liberational model is concerned with participation and tackling unequal social structures. Both models can be detected in professional approaches to 'empowering practice' (Simon, 1990).

In health, calls for empowering practice are made in the fields of nursing, health promotion and mental health (Campbell and Lindow, 1997; Fraher and Limpinnian, 1999; Gibson, 1991). The development of empowering social work practice in line with anti-oppressive values is also advocated (Braye and Preston-Shoot, 1995; Parsons et al, 1998). A review of this literature suggests that professions are operating according to different definitions of empowerment, with the individualised, consumerist model more prominent amongst health professions (Anderson, 1996) while social work's empowerment practice is more congruent with the liberational model (Adams, 1996; Braye and Preston-Shoot, 1995).

Much of the health profession's literature on empowerment refers to how professionals can empower service users (e.g. Ekpe, 2001; Gibson, 1991). However, it is argued in this dissertation that empowerment is not something that professionals can 'do' to others (Dowson, 1997; Jack, 1995). As Read and Wallcraft (1992) state, "no-one can give power to another person, but they can stop taking their power away" (p.5), echoing Simon's (1990) argument that:

> Empowerment is... a process capable of being initiated and sustained only by the agent or subject who seeks power or self-determination. Others can only aid and abet in this empowerment process... by providing a climate, a relationship, resources, and procedural means through which people can enhance their own lives. (p.32)

Indeed, acknowledgement of individual agency and rights to self-determination are seen by Deegan (1997:14) as key to the empowering potential of professional practice.

Interestingly, Beresford and Croft (1993), well known service user advocates, define empowerment as "making it possible for people to exercise power and have more control over their lives" (p.50), implying someone else 'empowering' people. Beresford clarifies his position in later work (Beresford and Trevillion, 1995:10), by

suggesting a facilitating role for professionals in supporting service users' empowerment. This latter point is important in highlighting that some disempowered people may require support to engage in empowerment processes[57].

Using the example of health promotion, Grace (1991) makes the important critical observation that the profession's commitment to 'empowerment' has tended to translate into controlling attempts to 'empower' communities according to predetermined, professionally-defined models, rather than facilitating the development of pre-existing skills and strengths. This criticism is important to bear in mind in the context of this doctoral research when considering the extent to which use of a predetermined and researcher-defined model such as PR can result in an empowering process for those involved.

Many social work authors refer to empowerment practice (e.g. Dalrymple and Burke, 1995; Parsons et al, 1998; Ward, 2000), the core aspects of which have been identified as: a value base concerned with social justice promotion, self-determination and self-actualisation; a theory base emphasising an understanding of oppression, the significance of power in social relationships, and the personal and social costs of belonging to a disempowered group; guidelines for the user/worker relationship focused on shared power and 'participant-driven' relations; and a social problem-solving approach to practice, with the professional as facilitator and resource rather than director of this process (Parsons et al, 1998). Strategies to facilitate empowerment at personal, interpersonal and environmental levels are advocated, acknowledging that power operates on all three levels. This model of empowerment practice therefore seems more in line with the liberational model, highlighting power and oppression (Ward, 2000).

Nonetheless, a paradox has been identified in being a professional committed to empowerment (Evans, 1992; Simon, 1990), due to the potentially disempowering nature of professionals' expertise and to their institutionalised positions (Pease, 2002:137). As 'street-level bureaucrats' (Lipsky, 1980), health and social care

---

[57] It should be noted, however, that such support would not necessarily need to come from professionals.

professionals also have considerable discretion to work in different ways according to their own values, including their conceptualisation of empowerment.

Baistow (1994) makes a detailed critique of the conceptualisation of empowerment as professional practice, expressing concern at the way in which, in professional fields:

> Empowerment... seems to be becoming essential to leading a better life. Therefore if you are unable to do it for yourself you may need professional assistance in doing so. Furthermore, you may need professional help to recognise that you are in need of this type of professional assistance. (p.37)

Baistow argues that this extension of professional intervention into areas of everyday life results in regulatory possibilities for empowerment thus conceptualised. It has been suggested that empowerment is in danger of being appropriated by professionals as a critical part of their role (Adams, 1998), thereby resulting in professionally-defined and service-focused approaches to empowerment in which service users have little say or control (McLean, 1995; Pease, 2002).

It can therefore be argued that health and social care professionals may be in a position to facilitate and support service users' empowerment but only if they are mindful of people's experiences of powerlessness and oppression and work with them in ways which do not reinforce these experiences. Furthermore, practice is likely to be most empowering if it adopts a strengths-focused approach, i.e. a "recognition of the power and capabilities that individuals already possess" (Fitzsimons and Fuller, 2002). The need for professionals to go beyond working at an individual level to support people to challenge oppressive social structures is also implied.

Examples of professionals working in this way exist in the mental health user/survivor movement, where some user groups working in line with a liberational model of empowerment have accepted professional workers as allies (Barnes, 1997a) who can provide access to skills, knowledge and practical support (Campbell, 1990). Many health and social care professionals are also responding to service users' criticisms of traditional approaches to research (Oliver, 1992) by attempting to engage in more participatory and empowering research work with service users (Ellis, 2000)[58].

---

[58] Service user involvement in research is discussed further in Chapters Four and Five.

Processes and levels of empowerment

Views differ on whether empowerment is a process, an outcome, or both (McLean, 1995; Simon, 1990). Empowerment has been identified as "both a means and an end" (Beresford and Croft, 1993:219) and "both in terms of process and goal" (Stevenson and Parsloe, 1993:6).

It has been suggested that empowerment is an outcome which results from developmental processes, both on a personal level as a 'sense' of empowerment and at a collective level as participation in political action (Rissel, 1994). However, viewing empowerment itself as an outcome suggests that it is a fixed and finite concept such that someone can definitively be said to 'be empowered'. If empowerment is instead conceptualised as a process of personal development leading on to broader collective action and participation (Gaster, 1996), this suggests a more fluid and dynamic process with possibilities for growth and change (Dalrymple and Burke, 1995). Viewing empowerment in this way also highlights that it is not necessarily a sequential and linear process, and that people engaged in empowerment processes may experience events and changes which are disempowering[59].

It is argued in this chapter that empowerment is most usefully conceptualised as an ongoing developmental process through which people increase their personal sense of power, choice and control, and use this to achieve improvements in their lives, and possibly in broader social conditions (Barnes and Bowl, 2001) (which could then be defined as *outcomes of an empowerment process).* Viewing empowerment as a process also implies that "it will look different for different people, organizations, and settings" (Rappaport, 1994:367) and that it will need to be considered and evaluated over time (Rappaport, 1987).

Indeed, much of the literature refers to empowerment as a process (e.g. Barnes and Walker, 1996; Kabeer, 1999). The often-quoted definition of empowerment given by the Cornell Empowerment Group is:

---

[59] Such disempowering events may be at a micro-level, for example in their interactions with professionals implementing policy, or at a macro-level, for example due to the introduction of more restrictive mental health legislation.

> Empowerment is an intentional, ongoing process centered in the local community, involving mutual respect, critical reflection, caring and group participation through which people lacking an equal share of valued resources gain greater access to and control over those resources. (Wolff, 1993:3)

Similarly, Fitzsimons and Fuller (2002) view empowerment as "the process by which people, organisations and communities gain and strengthen the skills and resources they need in order to have greater control over their lives" (p.487). If empowerment is viewed as a developmental process, this reinforces the argument that empowerment is not something that professionals can 'do' to people, although the provision of support to engage in such a process may be important.

Common elements of the empowerment process have been identified as "personal development, participation, consciousness raising and social action" (Rissel, 1994:41). Indeed, this implies that empowerment processes operate at individual, group, organisational and societal levels (Neath and Schriner, 1998; Ristock and Pennell, 1996), countering oppression on different dimensions.

Empowerment at an individual level has been identified as involving positive change at the levels of feelings, ideas, and action (Dalrymple and Burke, 1995:56), and can helpfully be defined thus:

> Individual empowerment occurs through the process of personal development. This entails both the growth of skills and abilities, as well as a more positive self-definition. (Staples, 1990:32)

Importantly, Dalrymple and Burke argue that this individual empowerment process is ongoing and circular, with change at one level enabling change at another.

It is important to note that individual empowerment should be viewed not as "merely a personality variable... but as the intersection between individuals and the societal structures in which they participate" (Segal et al, 1995). Fitzsimons and Fuller (2002) similarly view empowerment as "a multi-level concept concerned with individual self-determination in the context of the social, economic and political structures within which the individual is embedded" (p.483).

From their thorough review of psychological literature, Fitzsimons and Fuller operationalise the concept of individual empowerment by identifying the following intra-psychic and behavioural components (Table 1).

Table 1: Intra-psychic and behavioural components of empowerment

Subjective/intra-psychic components	Behavioural components
• Sense of control or self-determination over goals and circumstances • Sense of self-efficacy or self-confidence in ability to achieve desired outcomes • More positive self-concept or increased levels of self-acceptance and self-esteem • Sense of being valued and respected by others, of being able to make an impact, a sense of connectedness to others • Sense of purposiveness, of causal importance, an active orientation towards advancing one's interests, a hopeful and motivated stance	• Having the social support necessary to facilitate the achievement of goals • Increased understanding and awareness of one's own interests, one's position in relation to others, and one's social and political position relative to the distribution of power • Acquisition of skills and competencies needed to achieve desired outcomes (e.g. interpersonal, practical, political and personal development skills) • Evidence of positive outcomes such as acquisition of competencies, changes in circumstances or achievement of goals • Participatory behaviour and involvement in relevant organisational structures • Engagement in behaviours to support empowerment of others, concern for common good

(Source: Fitzsimons and Fuller, 2002:486)

It is argued that any definition of individual empowerment should recognise "the importance of connectedness in human life" (Higgins, 1999:289) and should therefore also include an emphasis on involvement in community (Laverack and Wallerstein, 2001:182). It has been suggested that for community or group empowerment to take place, individuals must have gone through a process of personal development leading to individual empowerment. Participation in groups is identified as important in this process, by providing social support, opportunities for consciousness-raising and dialogue (Lee, 2001), learning new skills, and a base for social action (Dominelli, 2002; Higgins, 1999). Articulating and sharing experiences of oppression can contribute to empowerment by making visible personal experiences and thereby encouraging people to value themselves (Dalrymple and Burke, 1995).

It is therefore suggested that group empowerment can enhance members' individual empowerment, as individual and collective empowerment interact (Dominelli, 2002). From this viewpoint, PR's emphasis on groupwork as the means by which problems are identified and solutions are sought could be seen as congruent with empowerment processes, despite Baistow's (1994) criticism that groupwork does not inevitably lead to collective action and community empowerment. However, it should be noted that individual empowerment will not necessarily lead to collective group empowerment and vice versa (Staples, 1990).

Finally, empowerment at a societal or structural level would essentially involve collective political action for social change to eradicate structural inequalities in society (Thompson, 1998:75).

Measuring empowerment

Evaluation of empowerment is a problematic endeavour, with a lack of consensus and difficulties in measuring whether and to what extent empowerment is 'occurring' (Dickerson, 1998; Kabeer, 1999), and relatively little discussion of evaluation in the British literature on empowerment. The range of strategies, solutions, people and time spans involved in empowerment makes it difficult to measure, particularly as the effects of empowering processes may take several years to become apparent (Baistow, 1994).

Due to pressures on organisations to evaluate services, there is a danger of empowerment being viewed as similar to 'quality', as a concept which can be 'appraised' by organisations (e.g. Herrenkohl et al, 1999). Indeed, some attempts to measure empowerment have used professionally-defined approaches such as 'performance indicators' and 'competencies' to assess levels of empowerment (e.g. Donlan, 1993), highlighting the potential 'lack of fit' between professional- and user-defined empowerment processes.

If empowerment is not to be reduced to an unrealistic and unitary concept for measurement purposes (Baistow, 1995), attempts to evaluate empowerment should include the views of the people concerned (Manning, 1998; Rappaport, 1987) and consideration of their specific social context (Fitzsimons and Fuller, 2002).

Therefore, rather than attempting to evaluate empowerment via one single measure, "each measurement, intervention and description in a particular context adds to the understanding of the construct" (Gibson, 1991:360).

This is a crucial argument in relation to the methodological approach used in this doctoral work to assess the extent to which PR processes were empowering in a particular context (as discussed in Chapter Six). Fitzsimons and Fuller (2002) highlight "the need for researchers to be sensitive to the meaning of empowerment in a particular setting since the meaning of personal control and the nature of resources and goals defined as important can vary from setting to setting and individual to individual" (p.487).

American researchers have attempted to measure empowerment amongst members of mental health user/survivor groups. For example, Segal et al (1995) developed empowerment scales after having observed users at four self-help organisations for a year. Their scales focus upon measuring the degree of individual empowerment, on a personal level (defined as the extent to which individuals feel that they have gained control over their lives), an organisational level (with regard to their degree of influence within organisational structures) and an extra-organisational level (with regard to their participation in political and civic activities in the wider community). Other elements of individual empowerment identified in this study include self-esteem, locus of control, hope, and self-efficacy[60].

Rogers et al (1997) also developed a scale to measure individual empowerment amongst mental health service users, by drawing upon definitions proposed by an advisory board of mental health survivor movement leaders in the United States. The scale includes five factors of empowerment: self-esteem – self-efficacy; power – powerlessness; community activism and autonomy; optimism and control over the future; and righteous anger (p.1044).

[60] Self-efficacy is defined by Segal et al (1995) as "the individual's confidence in his or her ability to be efficacious in common life activities and in political actions" (p.225).

However, such studies have been criticised for focusing upon "the achievement of individual empowerment through collective action rather than any notion of collective empowerment itself" (Staples, 1990:37) and for only focusing upon people active in user groups (Dickerson, 1998). While such work is clearly valuable in illuminating aspects of empowerment for the people concerned, it cannot be assumed that scales developed in this way will be relevant to people who are not active in user groups, reinforcing the need for studies of empowerment processes to focus upon their specific social context.

Manning (1998) carried out qualitative research on empowerment with mental health service users and found that participants viewed empowerment as being about: choice and the ability to have control over their own lives; respect, including being listened to, and self-respect; 'coming out' about their mental health status to other people; involvement in and belonging to a community; contributing to and helping others; and information and education (p.95-96). These views do not fully accord with the scale items proposed by Segal et al and Rogers et al, reinforcing the arguments that empowerment varies according to context, time and the individuals involved, and that qualitative methods can be useful in exploring the richness of the concept of empowerment (Fitzsimons and Fuller, 2002).

The debate over whether empowerment is a process or an outcome also has some relevance in terms of measuring empowerment. If empowerment is viewed as a continuous developmental process, then a sole focus on outcome variables is likely to ignore important process aspects which may have contributed to positive outcomes (Fitzsimons and Fuller, 2002; Laverack and Wallerstein, 2001)[61].

In the field of mental health, recovery has been identified as a concept similar to empowerment (Allott and Loganathan, 2002), and as such merits exploration to identify ways in which the two might be related (Deegan, 1997).

---

[61] These points on appropriate ways of measuring the richness of empowerment processes occurring in a particular context will be further considered in Chapter Six.

Recovery

Recovery has been proposed as an emerging mental health paradigm (Anthony, 1993; Ridgway, 2001), developed by service user movements in America and New Zealand in the late 1980s and early 1990s (Ralph, 2000)[62], and more latterly advocated by the British user movement (Turner, 2001). The recovery paradigm is rooted in the assertion that people with experience of mental distress are human subjects who can act to change their own situation, rather than passive objects to be acted upon (Deegan, 1996). This approach highlights that people can and do recover from mental distress (Coleman, 1999b), a position in stark contrast to that of traditional mental health services which are seen to aim for 'maintenance' and to have very low expectations of people ever recovering from distress (Curtis, 1997; Lapsley et al, 2002). Indeed, it is noted that people have to recover not only from their experiences of mental distress, but also from the damaging consequences of being labelled 'mentally ill' (Anthony, 1993; Deegan, 1997; Lapsley et al, 2002).

A wealth of 'first-person' accounts of recovery by people with experience of distress (e.g. Coleman, 1999b; Deegan, 1997; Reeves, 2000) and 'second-person' descriptions via research exploring people's experiences of recovery (e.g. Lapsley et al, 2002; Onken et al, 2002) has been published in recent years. As commented by Read (2001a) in the introduction to a collection of user accounts of surviving and recovering from mental distress (Read, 2001b), these strengths-focused, inspirational narratives highlight "the resourcefulness, imagination and determination of people who have overcome the most challenging of internal and external obstacles to rescue their lives" (2001a:5).

Journeys of recovery

Similar to empowerment, recovery is most often conceptualised as a process rather than an outcome (Allott and Loganathan, 2002; Turner, 2001). As Deegan (1997) suggests from her experiences:

---

[62] In New Zealand and parts of North America, recovery has been adopted as the guiding principle for mental health services (Lapsley et al, 2002; Turner, 2001).

> After twenty-three years of living with this thing it still hasn't gone away. So I figure that I'm never going to get 'cured' but I can be in recovery. Recovery is a process, not an end point or a destination. (p.20)

For such reasons, many service users talk about recovery as a journey (Coleman, 1999b; Ridgway, 2001), to emphasise its ongoing and non-linear nature (Anthony, 1993) (similar to the empowerment process discussed above).

The unique and deeply personal nature of each individual's journey of recovery is emphasised by authors (Deegan, 1996; Lapsley et al, 2002), therefore suggesting that measuring recovery is likely to be difficult (Jacobson, 2001; Ralph, 2000). Indeed, Jacobson (2001) argues that people are likely to use different explanatory models to understand their experiences[63], which will influence the nature of their recovery. Despite this uniqueness, however, common themes can be identified in people's accounts.

Common themes of recovery processes

Definitions of recovery tend to share an emphasis on regaining control over one's life (Deegan, 1997; Ralph, 2000; Repper, 2000), re-establishing a sense of self and purpose (Allott and Loganathan, 2002; Coleman, 1999b), and living a full and valuable life not dominated by mental distress (Turner, 2001). The following are illustrations of such definitions:

> Recovery... is about regaining what may have been lost: rights, roles, responsibilities, decisions, potential, and support. It is not about symptom elimination, but about what an individual wants in his/her life... (Curtis, 1997:13)

> Recovery is... a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. (Anthony, 1993:15)

Other themes of recovery identified by authors include: personal responsibility, education, peer support and self-advocacy (Mead and Copeland, 2000); new life goals and community integration and participation (Grierson, 2001; Ridgway, 2001); emotional growth and transitions in identity (Lapsley et al, 2002); choice, including taking responsibility for choices made rather than allowing other people to make

---

[63] Such models are likely to include biological, abuse/trauma, spiritual/philosophical, political, and spirit-breaking explanatory frameworks (Jacobson, 2001).

choices on one's behalf (Coleman, 1999b); and recognition that recovery can be occurring even if symptoms persist and 'relapses' occur (Anthony, 1993; Deegan, 1997).

Support from a wide range of people, including others in recovery, family, friends, co-workers and health and social care professionals (when considered appropriate) is identified as a key element in the recovery process (Anthony, 1993; Philip and Nelson, 2001; Reeves, 2000). Belief in a person's ability to recover is also critical (Onken et al, 2002:viii).

In relation to environmental conditions, basic material resources such as adequate income, housing, health care and transport are also viewed as helpful in enabling people to engage in processes of recovery (Onken et al, 2002).

Ralph (2000) identifies four dimensions of recovery from these personal accounts, outlined in Table 2.

Table 2: Dimensions of recovery

Dimension of recovery	Explanation
Internal factors	Factors within individuals, including awareness of the impact of distress, recognition of the need to change, insight about how change can begin, and determination to recover.
Self-managed care	Extension of internal factors: ways in which people manage their own mental health and cope with difficulties and barriers they face.
External factors	Interconnectedness with others; supports provided by family, friends and professionals; and having people who believe that they can cope with and recover from experiences of mental distress.
Empowerment	Combination of internal and external factors: internal strength is combined with interconnectedness to provide self-help, advocacy, and caring about what happens to ourselves and to others.

(Source: Ralph, 2000:11-12)

With regard to Ralph's (2000) second dimension of recovery, self-managed care, a wealth of information on practical strategies and tools for recovery is accumulating as people in recovery share their experiences of self-management via publications, training courses, research and self-help groups (e.g. Curtis, 1997; Reeves, 2000).

Strategies for recovery: self-management

Self-management and self-care have been described thus:

> ...each person comes to develop a dynamic and highly personalized set of self-help strategies, resources and coping skills. They learn to self-monitor and self-control their psychiatric symptoms, build important supports and contend proactively with stress and challenge, so that symptoms lessen or do not recur... (Ridgway, 2001:338)

Research has found that people with experience of mental distress use a wide range of strategies to self-manage symptoms of distress and to lead a full life (Alverson and Becker, 1995; Kennedy et al, 2000; Ridgway, 2001; Sayer et al, 2000), with individual choice and self-determination of central importance. Some of these strategies are outlined in Table 3 (p.89)[64].

Deegan's (1997) account of her approach to self-management as part of her journey of recovery illustrates how some of these strategies might be used:

> ...to me being in recovery means that I don't just *take* medications... I *use* medications as part of my recovery process... Sometimes I use medications, therapy, self help and mutual support groups, friends, my relationship with God, my work, exercise, spending time in nature – all these things help me remain whole and healthy even though I have a disability. (p.21)

With regard to symptom management, Carr's (1988) community survey of 200 people with a diagnosis of 'schizophrenia' identified use of a wide range of active coping techniques for symptom management, including behaviour change, socialisation, cognitive control, and use of medical care[65].

---

[64] These strategies were obtained from research into self-management by people with a diagnosis of 'schizophrenia' (Martyn, 2002).

[65] Carr (1988) provides more detailed explanation of these categories of coping techniques: behaviour change includes techniques of distraction, change in physical activity, indulgence and task performance; socialisation refers to either increased or decreased interpersonal contact; cognitive control includes suppression of ideas and perceptions, shifted attention towards comforting or less disturbing ideas, and problem solving; and use of medical care entails taking additional medication, changing medication, and going to a primary or secondary care setting.

Table 3: Self-management strategies

Self-management strategy	Examples
Maintaining morale and finding meaning	• Developing positive personal attitudes and beliefs • Exploring and understanding experiences • Religion and spirituality
Building relationships with other people	• Family and friends • Other service users • Health and social care professionals • Colleagues • Community members
Coping with day-to-day life	• Using basic living skills and self-care • Healthy living
Personal self-management	• Self-assessment • Goal setting • Risk-taking
Interpersonal self-management	• Building relationships with others • Learning to communicate
Emotional self-management	• Relaxation • Stress management
Thriving, by building a fulfilling and satisfying life	• Occupation • Recreation and a social life
Managing 'having mental distress'	• Access to information • Managing medication • Relapse management • Symptom management • Managing the nature of relationships with health care professionals • Talking therapies • Complementary therapies

(Source: Martyn, 2002)

Professional involvement in recovery?

Similar to the debate about empowerment as professional practice, concern has been expressed that recovery might be co-opted by professionals as just another treatment approach (Curtis, 1997) or used as a reason to withdraw services from people who are considered to be 'recovered' by some professionally-defined standard (Ralph, 2000).

Similar to empowerment, it is clear that recovery can occur without any professional involvement (Anthony, 1993), yet positive relationships with mental health professionals can enhance recovery (Allott and Loganathan, 2002; Mead and

Copeland, 2000) if this professional involvement has been actively chosen by an individual as appropriate for their recovery journey (Ridgway, 2001).

Coleman (1999b) suggests that professionals can facilitate a recovery approach by focusing on wellness not 'illness', using personal recovery plans with service users, and concentrating on people's strengths and positives rather than 'difficulties' and 'symptoms'. Deegan (1996) argues that professionals supporting a recovery process also need to allow people to take risks and have the opportunity to fail.

Recovery and empowerment

The concepts of recovery and empowerment are clearly closely related, not least because "the process of personal recovery has at its very heart the reclamation of personal power" (Coleman, 1999b:48) and the exercise of self-determination, choice and independence (Anthony, 1993; Onken et al, 2002).

Deegan (1997) argues that empowerment and recovery must go "hand in hand" (p.22) as people also have to "take back our power to think critically and, as individuals and as a group, to reclaim our power over our own lives and the resources that effect our lives" (p.22). Like empowerment, recovery is identified as a process which involves regaining control (Deegan, 1997) and re-establishing a positive sense of self (Coleman, 1999b). Internal strength and connectedness with others (for example, via self-help and advocacy) are viewed as elements of empowerment critical to the recovery process (Ralph, 2000).

Before drawing conclusions about the nature of empowerment, the terms 'involvement' and 'participation' will also be explored due to their frequent use in debates about empowerment.

Defining terms: involvement and participation

The terms 'involvement', 'participation' and 'empowerment' are often used interchangeably, yet each incorporates a range of underpinning values and ideological positions (Ward, 2000): "at one end of the spectrum lie consumerism and linkages with the New Right, and at the other, citizen action and control" (p.45). The following sections will explore models of involvement and participation to consider their relevance to empowerment.

Defining involvement

There is a lack of consensus about the meaning of involvement (Beresford and Trevillion, 1995; Braye, 2000), with competing agendas and different interests of service users and providers (Campbell and Lindow, 1997; Ferguson, 1997). The identification of different models of involvement, based upon varying philosophies, contributes to a clearer understanding of the concept.

Two main models of user involvement have been highlighted, termed the consumerist and democratic models (Beresford and Croft, 1993; Fleming and Golding, 1997). The consumerist model, based on the market model of services, emphasises individual choice, attracting 'customers' and consulting people to provide services that they want (Fleming and Golding, 1997:3). This model has been developed by service providers and organisations concerned with improving their efficiency and market competitiveness (Lupton et al, 1998):

> ...its purpose is to influence individual consumption of services. Services may become more responsive, flexible and relevant, but remain essentially owned and controlled by the agency or professionals involved. (Braye, 2000:18)

In contrast, the democratic model of involvement focuses upon people's citizenship rights and responsibilities (Croft and Beresford, 1993; Lupton et al, 1998):

> A democratic model (seeks) improvements not just in service provision but in all aspects of social experience... The goals will thus reside in the wider avenues of citizenship in which oppression and exclusion are experienced... The focus is upon participatory rights rather than welfare needs. (Braye, 2000:18-19)

It has been argued that the extent and nature of involvement is likely to be different within each of these models, with consumerism viewing involvement activities as discrete events while democratic approaches conceptualise involvement as an ongoing participatory process aiming to enable people to take action to make changes in their lives (Lupton et al, 1998:45-46).

The consumerist approach to user involvement has been dominant in health and social care services (Barnes and Walker, 1996; Williamson, 1993), despite criticisms of the application of the notion of consumerism in a public service context. These criticisms include the limited scope for production of particular services to increase in response to user demands when public resources are limited. This predominance of the consumerist model of involvement may be partly due to the highly managed nature of health and social care services, which would make the democratic kind of involvement much harder to encourage due to its broad focus on citizenship and 'bottom-up' action (Braye, 2000). Consumerism's dominance has led some to argue that user involvement as a public service principle following the New Right's individualistic welfare approach has become "discredited" and "tokenistic" (Ward, 2000).

The consumerist and democratic models of involvement imply different levels and forms of activity, involving varying degrees of power. These are described below.

Types of involvement

A spectrum of user involvement can be identified (Campbell and Lindow, 1997), with forms of involvement varying with the degree of control involved (Barker et al, 1999). Philpot (1994) outlines a continuum of user involvement in mental health services (Figure 6, p.99)[66]. This demonstrates that involvement can include informing change, influencing change, deciding change or service users making changes by running their own services (Croft and Beresford, 1993:19).

Few authors make explicit links between different models of involvement and corresponding levels of activity. Croft and Beresford (1993), for example, advocate a

[66] Philpot notes that different points on this continuum may co-exist within any one service

democratic approach to involvement but are not then explicit about how this might be implemented. Nonetheless, it would seem to be implied that the democratic model of involvement is more concerned with activities involving partnership and control where users have more influence over the agenda, than those involving information and consultation, which tend to be conducted according to a predetermined consumerist service agenda.

Figure 6: Philpot's continuum of user involvement in mental health services

MINIMUM INVOLVEMENT	**information**	Service users are given information about developments through talks, newsletters or leaflets.
▲		
|	**consultation**	A variety of means (e.g. surveys, stakeholder conferences, smaller meetings) are used to elicit user views which will be taken into consideration when decisions are made.
|	**partnership**	Managers, professionals and users work together to plan and reach decisions about the service.
▼	**user control**	Budgets may be delegated to users to run their own services or carry out pieces of work on behalf of commissioning agencies, e.g. quality monitoring.
MAXIMUM INVOLVEMENT		

(Source: Philpot, 1994:4)

Involvement and empowerment

With regard to the relationship between involvement and empowerment, a difference between the two concepts can be identified (Grant, 1997). In line with Croft and Beresford's (1993:19) observation that "not all involvement is necessarily empowering", Dowson (1997) argues strongly against conflating the two concepts, as forms of involvement towards the minimum end of Philpot's (1994) continuum are unlikely to accord any real power to service users.

Nonetheless, it can be argued that user involvement in service delivery may have broader implications (Schafer, 1996), contributing to empowerment via "the cumulative effects of activities which have the initial purpose of sensitising service

delivery to user needs and preferences" (Grant, 1997:124). Therefore, relatively small user involvement initiatives should not necessarily be dismissed in favour of the more ambitious objective of empowerment.

Although largely overlooked in the literature, it is important to distinguish between different models of both involvement and empowerment. Croft and Beresford's (1993) models of consumerist approaches to involvement (professionally-led and service-focused) and democratic approaches (user-led and focused on citizenship) are very similar to the consumerist and liberational models of empowerment they identify (Croft and Beresford, 1995). This suggests that involvement defined according to the consumerist model might lead to empowerment in the consumerist sense of people's ability to make informed choices between services, while democratic involvement would contribute to empowerment in the liberational sense of people challenging their oppression in order to participate in society as full citizens.

Defining participation

Although the two terms are frequently used synonymously, the concept of participation appears to be narrower than that of involvement as it implies some level of influence over an organisation's decision-making processes (Lupton et al, 1998; Philpot, 1994).

Similar to both empowerment and involvement, participation is a term with varying interpretations (Braye, 2000; Litva et al, 2002). Three approaches to participation have been identified: managerial, market-based, and rights-based (Biehal, 1993). Managerial approaches are concerned with using participation to enhance effectiveness of service delivery, while market approaches equate participation with consumer choice in the 'quasi-market' of public services. In contrast, a rights-based approach identifies "increased participation in decisions about public services as a means of ensuring the rights and dignity of service users as citizens" (Biehal, 1993:444). Similarly, Morrissey (2000) argues that an instrumental approach to participation is one which views it as a means to an end, leading to successful project outcomes, while a democratic approach is more concerned with participation's developmental potential for individuals. There are again parallels here with different

models of both empowerment and involvement, distinguishing between professional, market-based approaches and democratic approaches concerned with citizenship.

Power is central to an understanding of participation (Croft and Beresford, 1996), and it can be argued that increasing participation means increasing users' power (Priestley, 1999). This is reflected in Arnstein's (1969) 'ladder' of participation, described below.

Arnstein's ladder of participation

The most widely used model of participation continues to be Arnstein's (1969) ladder of citizen participation (Figure 7)[67]. This typology outlines a range of activities and citizens' corresponding degree of power (while acknowledging that these are not mutually exclusive categories, and that 'the powerless' and 'the powerful' are heterogeneous groups).

Figure 7: Arnstein's ladder of citizen participation

8	Citizen control	Degrees of citizen power
7	Delegated power	
6	Partnership	
5	Placation	Degrees of tokenism
4	Consultation	
3	Informing	
2	Therapy	Non-participation
1	Manipulation	

(Source: Arnstein, 1969:217)

[67] Arnstein's model relates to direct participation activities, where service users have personal contact with those involved in the decision-making process. Indirect participation also occurs, involving "all other activities in which people consciously attempt to exert some influence on decision making and policy formulation, such as voting, membership of political parties, campaigning and pressure group activity" (Lupton et al, 1998:51). This indirect

The 'non-participation' levels (One and Two) are seen as having the aim of 'curing' or 'educating' people rather than enabling them to participate in planning, while Levels Three to Five involve degrees of tokenism in that they entail no power to ensure people's voices are heard by those with power. Levels Six to Eight represent increasing degrees of power in decision-making for citizens[68].

Arnstein's model has been criticised for its neglect of the role of professional expertise in decision-making. It could be argued that in order to understand complex issues, citizens may wish to draw upon professionals' expertise (Lupton et al, 1998). Arnstein's model can also be criticised for masking the differences in power and domination amongst citizens by presenting participation as involving united interests (Atkinson and Cope, 1997). Even at the level of citizen control, it could be argued that projects are still resourced by statutory organisations such as local authorities and that these organisations are therefore able to exert a certain degree of control over the nature of participation.

Nonetheless, Arnstein's model is valuable for its emphasis on power as central to understanding participation, "both the nature and extent of formal powers present in various participatory mechanisms and the degree of actual power and influence exerted" (Hallet, 1987:11). It also allows for consideration of empowerment as a developmental process, as activities enable users to progress up the 'ladder' towards fuller participation and control over time (Lupton et al, 1998).

---

participation therefore refers to broader participation in civic and community life rather than direct participation in decision-making in organisations, which is the focus of the above literature.

[68] Arnstein (1969) explains her categorisation of each of the levels thus. Manipulation is defined as "the distortion of participation into a public relations vehicle by powerholders" (p.218), for example by placing people on advisory boards which 'rubberstamp' decisions. Therapy is viewed as an invidious form of 'participation' in that "citizens are engaged in extensive activity, but the focus of it is on curing them of their 'pathology' rather than changing the racism and victimization that create their 'pathologies'" (p.218). Informing often involves only a one-way flow of information from providers, which allows people little chance to influence decisions. Arnstein argues that consultation must be combined with other forms of participation otherwise it is "a sham since it offers no assurance that citizen concerns and ideas will be taken into account" (p.219). Placation, for example placing a few people on public bodies where powerholders are still in the majority allows people some level of influence, but tokenism is still involved. Partnership entails a redistribution of power via negotiation between powerholders and citizens who share planning and decision-making responsibilities, while in delegated power, citizens have "dominant decision-making authority over a particular plan or program" (p.222). Finally, citizen control is "that degree of power (or control) which guarantees that participants or residents can govern a program or an institution, be in full charge of policy and managerial aspects, and be able to negotiate the conditions under which 'outsiders' may change them" (p.223).

Participation, empowerment and involvement

There is little explicit reference in the participation literature to links with empowerment, although some authors describe participation as a stage in the empowerment process leading to greater decision-making power (Karl, 1995). It has also been suggested that participation can contribute to people's individual empowerment (Higgins, 1999; Zimmerman and Rappaport, 1988).

Following the arguments developed in this chapter, it appears that different models of participation might lead to empowerment in different senses. The market-based approach to participation might contribute to empowerment in the consumerist sense, while the rights-based participation approach is more congruent with the liberational model of empowerment. The degree of power service users can exercise at different levels of participation will also influence the empowering nature of that form of participation.

The distinction between participation and involvement in the literature is also not entirely clear: in most cases, writers appear to be referring to very similar concepts and processes, merely using different terminology. Several authors use the terms interchangeably (e.g. Braye, 2000) or use involvement as a general term which includes participation (e.g. Lupton et al, 1998). There is some suggestion in the literature that participation refers to levels of involvement which give users power and control over significant decisions, which would seem to imply that participation is a 'subset' of involvement.

The strong policy push towards greater user involvement and participation in service planning and delivery over recent decades has tended to have a consumerist emphasis. However, service user groups are increasingly arguing for participation in services towards the higher levels of Arnstein's (1969) ladder of participation, namely partnership and user control of services, rather than the minimum levels of information and consultation. If participative work which accords service users more control and power can be developed within statutory services, opportunities for a more liberational form of empowerment may increase.

Conclusion

It is concluded that empowerment is a contested concept with different meanings and underpinning ideologies, and competing discourses between service users, providers and policy makers. It is important to ensure that any definition of empowerment is underpinned by a theory of power, yet this link is often not made in the literature. It is proposed that considerations of power in this regard need to go beyond 'constant-sum' approaches which view individuals as having power to give to or withhold from others, to a more complex understanding of the various levels at which power operates (as discussed in Chapter Two), and the way in which empowerment processes might therefore function at different levels. The dynamic nature of power relations suggested by Foucault also has implications for empowerment strategies.

The consumerist model of empowerment is primarily concerned with increasing people's say within services. It is argued that this model narrows the debate on empowerment by only considering people in relation to services. In contrast, the liberational model of empowerment is concerned with overcoming oppression and discrimination to secure people's citizenship rights within society. It is recognised that an important part of overcoming oppression and discrimination for some service users may relate to their contacts with services. Nonetheless, the liberational model of empowerment offers the opportunity to focus on broader issues relating to citizenship rights and preferred status within society, possibly via collective action by service user groups. This does not negate any role for professionals and their organisations within this process, particularly as they are likely to be in close contact with marginalised people. Rather, it suggests that if service users so desire, professionals should work to support people to develop their own power both personally and collectively, which may then extend beyond their contact with services.

Despite claims in the professional literature to the contrary, there is a persuasive argument to suggest that professionals cannot give power to service users, although they can work in ways which facilitate or enable the development of people's personal and collective power. Claims to 'empowering practice' need to be explicit about this important distinction, as there is a danger of professionals appropriating

'empowerment' as another aspect of people's lives in which they can claim to play a vital role.

Related to this is the issue of whether empowerment is a process or an outcome. Although empowerment might be seen as an outcome in terms of 'feeling empowered', this suggests that an end-point can be reached where empowerment has 'occurred'. It is argued in this chapter that empowerment is not a fixed or finite concept, but a dynamic and fluid process operating at different levels. It is therefore suggested that individual empowerment be viewed as an ongoing process of personal growth and development, through which people may be enhancing their sense of personal power, control, confidence and self-esteem, developing a more positive self-definition, obtaining desired information, enhancing their skills and abilities, asserting their personal needs, and influencing the ways in which these are met in order to achieve improvements in their personal circumstances. This personal empowerment may then lead on to group empowerment, engaging in collective consciousness-raising and participating in action with others to achieve broader change in resource allocation, decision-making, service configuration and social structures if they so desire. This definition of empowerment, drawn from the literature reviewed, will be used as a basis for consideration of the extent to which the participatory research undertaken for this doctoral work facilitated empowerment processes for those involved.

People with experience of mental distress are increasingly emphasising recovery as a paradigm for conceptualising their experiences. The literature on recovery overlaps with much of that on empowerment in its common emphasis on regaining control over one's life, re-establishing a positive sense of self and purpose, making choices and exercising self-determination, and supporting others. It can be seen that empowerment in the liberational sense is considered by people with experience of mental distress to be critical to their journeys of recovery.

The concepts of involvement and participation have also been explored for their relationship to empowerment. It is concluded that the forms of involvement and participation most likely to contribute to processes of empowerment as defined according to the liberational model are those in which service users have power and

which facilitate their development as citizens with control over their lives as a whole rather than merely as service users functioning within professionally defined systems.

The next chapter of this dissertation draws upon the theoretical and conceptual literature critically analysed in the first three chapters to contextualise empirical evidence on the nature of oppression, power and empowerment experienced by mental health service users in Britain.

Chapter Four: Oppression, power and empowerment in the lives of mental health service users

Introduction

This chapter reviews empirical data on mental health service users' experiences of oppression and the exercise of power in the psychiatric system and more broadly in British society. These data are critically analysed using theoretical conceptualisations of oppression, power and empowerment explored in earlier chapters, for example Keating's (1997) model of oppression and Foucault's (1977) work on disciplinary power.

Themes explored include experiences of inpatient psychiatric services, and oppression and power relations in the everyday lives of people with experience of mental distress (for example in relation to employment, general health services, and housing). The media's influence on societal attitudes towards people in mental distress is explored in relation to oppression's socio-cultural dimension.

The impact of oppression is considered, as are constraints on mental health service users' citizenship rights. People's experiences of the ongoing shift from institutional to community mental health service provision are explored, and implications of the use of coercive and compulsory practices in the community are discussed.

Strategies for empowerment employed by people with experience of mental distress in the UK are then highlighted, for example action by user/survivor groups, user-controlled research and education, and user involvement in statutory service planning and delivery. The British policy context is examined to explore the extent to which government policy facilitates user empowerment. Links between strategies for empowerment and levels of empowerment are also made.

The voices of mental health service users

A 'user voice' has traditionally been absent from professionals' accounts of mental health service users' experiences (Barham, 1997; Barnes, 1997a; Langan and Lindow, 2004), reflecting the professional power involved in defining discursive

formations of mental health and 'illness'. However, a growth in publications giving a voice to British service users and survivor activists has occurred over the last twenty years (e.g. Beeforth et al, 1990; Beresford, 1997; Campbell, 1996; Dunn, 1999; Lindow, 1995; O'Hagan, 1993; Rogers et al, 1993; Women in Mind, 1986), highlighting 'subjugated knowledges' (Foucault, 1980) to challenge professional, 'scientific' discourses.

Rogers et al (1993) argue that "the views of users of mental health services are valid in their own right... they are a legitimate version of reality... which professionals and policy-makers should no longer evade or dismiss" (p.13). Similarly, Dalrymple and Burke (1995) state that "it is from the experiences of people who have been marginalized, who have had their rights denied or violated, that we can understand what is meant by oppression" (p.15). This chapter therefore aims to ensure that service users' experiences are prominent in discussions of oppression and power relations.

Experiences of inpatient psychiatric services

Inpatient psychiatric services are identified by service users as a significant source of oppression and disempowering treatment (Goodwin et al, 1999; Lindow, 1995; Rogers et al, 1993). The socio-political oppression embedded in psychiatry's structures can be seen to interact with oppression's psychological dimension in people's accounts of inpatient provision. These dimensions of oppression are reinforced by cultural norms that identify people in distress as 'inferior', 'dangerous to others' and therefore in need of segregation. The operation of disciplinary power (Foucault, 1977) is also evident in inpatient psychiatric settings (see p.110).

Compulsory admission and treatment

Current British mental health legislation, as contained within the Mental Health Act 1983 (and likely to be continued in the new Act currently being considered), is criticised for its provision for compulsory hospital admission and treatment (Lindow, 1995), and the oppressive social control role this plays (Barnes and Shardlow, 1997; Pilgrim and Rogers, 1996). The exercise of this state-mandated professional 'power over' people (Wilding, 1982) is a clear example of an oppressive practice which has

both a socio-political and socio-cultural dimension, and a personal, psychological dimension (in terms of people's subjective experience of compulsory practices).

Common themes of oppression include the denial of rights (Thompson, 1993) and unnecessary restrictions of personal freedom (Keating, 1997), both of which apply to the use of compulsory admission and treatment. Indeed, it can be argued that such coercive legislation implies that the liberty of people diagnosed with 'mental illness' is of less value than that of the general population (Campbell and Heginbotham, 1991).

There is also evidence to suggest that the threat of compulsory admission is often used by professionals to exercise power by pressurising people to agree to be admitted (Rogers et al, 1993). Once admitted voluntarily, health professionals can then apply for people to be compulsorily detained, further undermining their 'voluntary' status (Symonds, 1998). Similar coercion and pressure with regard to treatment is noted by Rogers et al (1993) from their survey of 516 service users:

> I was told that I would be sectioned if I didn't take the anti-depressants. (Service user, p.166)

Both the threat and actual use of violence or coercion have been identified as key elements of oppression (Brittan and Maynard, 1984; Keating, 1997), as illustrated by Lindow's (1995) account of her experiences in psychiatric hospitals:

> They... treated me violently... They legally and illegally prevented me from leaving the hospitals by using the Mental Health Act and by taking my clothes away and forbidding me to leave... Various members of mental health teams exploited me sexually. (p.203-204)

The use of compulsory treatment is widely criticised for introducing coercive elements into 'caring' services and relationships (Barnes et al, 2000; Campbell and Heginbotham, 1991). Compulsory admission and treatment also have implications for user involvement in services as a strategy for empowerment, as "there is no incentive... to provide choice and attractive services if users can be compelled to receive them" (Lindow, 1995:206).

'Total institutions' and disciplinary power

The 'asylum' or psychiatric hospital, as the primary location of psychiatric treatment for several decades, is the focus of many criticisms of the treatment of people experiencing mental distress. In his seminal work 'Asylums', Goffman (1961) identifies a psychiatric hospital as a 'total institution', defined as "a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (p.11).

Total institutions have a clear physical and social split between staff and 'patients', and communication is restricted between the two groups. Goffman argues that admission to a psychiatric institution has several negative effects on individuals, including 'disculturation' and 'mortification'[69] (see p.19).

The characteristics of Goffman's 'total institution' and Foucault's (1977) disciplinary power (such as strict control of time, space and activity) can be identified from inquiries into British psychiatric hospitals in the 1960s and 1970s (Muijen, 1996), which revealed human rights violations and institutional abuse (Brackx, 1989). Oppressive practices such as regimentation and application of sanctions could still be seen in many British psychiatric institutions in the 1990s (Sines, 1994:895), contributing to a loss of dignity and sense of identity for people (Rogers et al, 1993).

Disempowerment and powerlessness

A key element of empowerment and recovery (as discussed in Chapter Three) is having choice and control over one's life (Barnes and Bowl, 2001). Feelings of disempowerment and powerlessness amongst mental health service users are a common consequence of the oppressive nature of psychiatric inpatient provision (Beeforth, 1993; Goodwin et al, 1999; Survivors Speak Out, 1988), partly due to the

---

[69] Examples of such 'disculturation' and 'mortification' include depriving people of the right to vote; taking away articles that mark identity, such as personal possessions; making people expose facts and feelings about themselves, which are then recorded and made available to staff; forcibly treating people with drugs; and taking away people's self-determination.

lack of such choice and control. O'Hagan (1993) reports that service users involved in her research felt most powerless and devalued in hospital[70].

A range of ways in which this disempowerment occurs has been identified by service users, all of which echo common themes of oppression (see p.40), namely: lack of choice in services and alternatives to drug treatment, and in daily activities such as eating and washing; lack of information about treatment, legal rights and welfare benefits; coercion and abuse, including use of drugs and ECT, enforced compliance, harassment and abuse of women, and abuse by staff (including violence and theft); and aspects of isolation and segregation, such as a lack of people to talk to (Goodwin et al, 1999; Read and Wallcraft, 1992; Sainsbury Centre for Mental Health, 1998).

Emphasis on physical treatments

Foucault's (1980) identification of the close link between knowledge and power relations is very relevant to consideration of the dominant use of physical treatments such as psychotropic drugs and ECT for people in mental distress, arising from the success of medical discourses of 'mental illness' (as discussed on p.16).

The negative effects of physical treatments have been extensively highlighted (Arscott, 1999; Breggin, 1993; Rose et al, 2004) yet remain largely unacknowledged or dismissed by psychiatrists (Rogers and Pilgrim, 2003). Side-effects of psychotropic drugs can include brain damage, Parkinsonism, tardive dyskinesia and sudden death from heart failure (Pilgrim and Rogers, 1994). Beeforth et al (1990) note problems experienced taking psychotropic drugs:

> ...many users hate taking drugs, which make you feel 'not yourself', which may have severe side effects that you usually have no warning about, which make you feel cut off and frighteningly alone... (page not numbered)

Department of Health statistics show that ECT was given to approximately 11,340 people in England in 1999, ten per cent of whom were likely to have received ECT without their consent (Johnstone, 2000). Distressing side-effects and adverse consequences of ECT include headaches, memory loss, nightmares and aggression (Arscott, 1999):

---

[70] O'Hagan's (1993) research was undertaken with survivors in Britain, the Netherlands and the USA.

> With each shock treatment, I felt more and more of myself slipping away. I couldn't remember things particularly the immediate past, but eventually even the more distant past had been erased. I was frightened by this. (Service user, quoted in Rose et al, 2004:290)

In further support of Foucault's (1980) contention that knowledge and power relations are closely linked, service users have highlighted the disempowering impact of the lack of information from professionals on treatments and their side-effects (Campbell, 1992; Goodwin et al, 1999; Mind, 2001a).

Participants in Rogers et al's (1993) survey expressed concern that drugs were both over-prescribed and misused as a way of controlling emotions and behaviour (see p.16-17). Drugs were also used punitively, which might be considered as an oppressive act of coercion, or as a 'disciplinary technique' (Foucault, 1977):

> Major tranquillisers were used as a method of punishment for non-compliance or for requesting discharge. Every time I was given major tranquillisers I was also given 'withdrawal of all privileges' - i.e. not allowed to... make or receive any contact with any outside source. (Service user, quoted in Rogers et al, 1993:133)

The use of such physical treatments stems from the dominance of psychiatry's medical model of 'mental illness'. However, mental health service users tend to take a more psychosocial view of their experiences, as noted by Rogers et al (1993):

> It was not these factors which *led* to their problem; these *were* the problem... Respondents saw their difficulties as meaningful in the context of their life experiences in regard to past disappointments, current dilemmas and future concerns. (p.176)[71]

This incompatibility between current medical discourse and user discourse about mental distress may be one reason why mental health service users so frequently report unhappiness with the physical 'treatment' they receive from professionals:

> They have a set diagnosis which they work to and treat with ECT and drugs. They do not search out the reasons for your illness with you so the illness just repeats again and again. (Service user, quoted in Rogers et al, 1993:50)

Indeed, rather than medical intervention, numerous studies show that what mental health service users want most when distressed is someone to talk to about their feelings (e.g. Rogers et al, 1993):

---

[71] Original emphasis.

> I felt isolated and felt there was a lack of communication. , I had assumed I would be able to talk about my problems with staff. (Service user, p.62)

Johnstone (2000) suggests that this conflict between "the *psychosocial* understandings and needs of those in distress and the *medical* assumptions and treatments of the professionals" (p.37)[72] is likely to make recovery rare within the psychiatric system, leading people to engage in journeys of recovery outside this system (see p.91).

Professional practice

A very strong power imbalance has been identified between service users and professionals in psychiatry (Lindow, 1995; Milroy and Hennelly, 1989; Rogers et al, 1993). Many elements of Wilding's (1982) work on forms and bases of professional power are relevant here, with mental health professionals enjoying power to define needs and problems, allocate or withhold resources, and exercise direct power over people's lives (see p.63-65). Lindow (1995) argues that "the power imbalance based on supposed expertise is probably the most pervasive feature of mental health services" (p.209).

Reports of oppressive professional practice may sometimes be more a result of structural contradictions within mental health workers' role than of neglectful or uncaring attitudes (Hopton, 1993). Some aspects of oppressive professional practice highlighted by service users, such as detaining and treating people against their will (Barnes et al, 2000), relate to workers' social control role, which they may be unwilling to emphasise (see p.69-71).

Nonetheless, a common observation is that professionals fail to listen to service users' voices and interpretations of their distress (Brewin, 1992; Sayce, 2000), viewing these as meaningless and 'lacking insight' (Barker and Peck, 1987) or using their words to assess and diagnose them (Campbell and Lindow, 1997). This silencing of people in distress, denying their experiences and effectively rendering them invisible, can again be seen as a way of sustaining oppressive power relations.

---

[72] Original emphasis.

Psychiatrists play a central role in the mental health system, and are therefore a focus of service users' criticisms. Participants in Rogers et al's (1993) survey were very critical of psychiatrists, for seeing service users only infrequently, displaying negative and patronising attitudes, and not providing enough information on treatment:

> Lacked understanding of my problems. Quite rude about things I couldn't do and humiliated me in front of other people. (Service user, p.49)

> They are passive. They don't provide any information regarding prognosis, diagnosis and treatment. They appear to be unimaginative and unsympathetic. (Service user, p.49)

Nurses are the most constant carers in psychiatric hospitals, and participants in both the Rogers et al (1993) and Goodwin et al (1999) user surveys identified positive experiences of nursing practice, including good physical care and respectful and empathic listening. However, participants also gave examples of poor nursing practice which echo themes of oppression highlighted earlier, including physical assault, forced injections, and cruelty and authoritarianism. Disrespectful attitudes of nursing staff were highlighted in Goodwin et al's survey, demonstrating an oppressive view of people in distress as 'inferior' (see p.45-46):

> Patients complained of being infantilised; of being told they had been 'naughty'; of staff who 'rolled their eyes' at them, or laughed when they inquired about discharge... (p.48)

The "apparent reluctance of nurses to spend time with patients" (Campbell and Lindow, 1997:10) is also identified by service users as a major problem during hospital stays (Barnes et al, 2000; Goodwin et al, 1999).

Multiple oppression in the mental health system

Oppression experienced as a result of a label of 'mental illness' is compounded by other forms of oppression (Braye and Preston-Shoot, 1995; Sayce, 1998). There is evidence that oppression in society such as racism, sexism, classism, ageism, ableism and homophobia translates into differential treatment by both primary and secondary mental health services (Barnes and Shardlow, 1997; Campbell and Lindow, 1997). Lindow (1995) suggests that this differential treatment is a result of the dominance within mental health professions of particular powerful social groups:

> The seats of psychiatry, psychology and social work are in the white, male middle class. More psychiatric service users are women than men... and poor than rich. It seems that the less like a white male psychiatrist one is, the more likely one is to be bio-medicalized. (p.209)

The interplay between psychological, socio-cultural and socio-political dimensions of oppression (Keating, 1997) is very apparent in relation to such multiple oppression. Evidence suggests, for example, that racism embedded within psychiatric structures and systems is reinforced by racist ideologies, ethnocentric theories and cultural assumptions, and is often played out at an individual level.

Research shows that Black people and people from minority ethnic groups experience additional oppression in the mental health system (Browne, 1996; Fernando, 2002; Patel and Fatimilehin, 1999; Sashidharan, 2001). For example, Black people and people from minority ethnic communities in Britain are "more often: diagnosed as schizophrenic; compulsorily detained under the Mental Health Act; admitted as 'offender patients'; held by police under Section 136 of the Mental Health Act; transferred to locked wards; not referred for psychotherapy; given high doses of medication; sent to psychiatrists by courts; (and) suffer(ing) from unmet need" (Fernando, 1995:34) compared to white people. A user survey also found that people from Black and minority ethnic communities were given less information about treatments and less choice of treatments than white people (Mind, 2001a).

Stereotypical assumptions about African-Caribbean people and 'dangerousness' appear to have contributed to their more coercive treatment by mental health services (Fernando, 1995). For example, fifteen per cent of special hospital patients in 1993 were African-Caribbean, despite this group constituting only one per cent of the general population (Samson, 1995)[73].

Women are similarly identified as receiving differential treatment within the mental health system (Barnes and Shardlow, 1997; Payne, 1996), with a disproportionate number of women receiving psychiatric treatment (Barnes et al, 2002; Samson, 1995) (as highlighted on p.29). For example, women in England are twice as likely

---

[73] It is noted that the National Institute for Mental Health in England was tasked by the British government with producing a strategy for reforming mental health services for people from Black and minority ethnic communities, in recognition of the racism and inequality currently experienced by these groups (NIMHE, 2003).

to receive ECT as men, including under section, with women over 65 comprising the largest group of people given ECT (Johnstone, 2000). Women have been over-represented amongst patients who are compulsorily admitted and treated (Hatfield and Mohamed, 1994; Williams, 1999)[74], and experience sexual harassment, abuse and assault on mixed-sex wards in psychiatric inpatient facilities (Payne, 1996)[75].

It is clear from such evidence that interplay between dimensions of oppression also operates for women, with individuals' sexism reinforced by sexist assumptions and theories, which are in turn embedded in psychiatry's patriarchal systems and structures (as discussed in Chapter One).

Oppression and power relations in the everyday lives of people with experience of mental distress

As detailed in Chapter Two, oppression arises from the creation and use of mechanisms of social stratification, whereby social groups are assigned differential status and power and thereby located in different structural positions (Thompson, 2001) (see p.45). Supposedly 'inferior' groups then experience oppression on psychological, socio-cultural and socio-political dimensions (Keating, 1997), which interact and reinforce one another on different levels.

Consideration of empirical evidence from mental health service users shows the way in which such processes of oppression operate in their everyday lives as a result of the application of a label of 'mental illness' (Barham and Hayward, 1996; Barnes et al, 2000).

---

[74] It is acknowledged, however, that this over-representation of women in sectioning has now been reversed with the shift to community care (Payne, 1996).

[75] However, it should be noted that the British Government aimed to phase out mixed-sex accommodation by the end of 2002 in 95 per cent of NHS Trusts (Mind, 2002a) and has developed a Women's Mental Health Services Strategy in recognition of the inappropriateness of much current provision for women (Barnes et al, 2002).

Nature of oppression and power relations experienced by people with a history of mental distress

Research with mental health service users shows the potentially devastating impact of oppression. A national survey of 778 mental health service users found that:

- 34% said they had been dismissed or forced to resign from jobs
- 69%... had been put off applying for jobs for fear of unfair treatment
- 47%... had been abused or harassed in public, and 14% had been physically attacked
- 25%... felt at risk of attack inside their own homes
- 26%... were forced to move home because of harassment
- 24% of parents said their children had been teased or bullied, or that they were afraid it would happen
- 25%... had been turned down by insurance or finance companies
- 50%... felt unfairly treated by general health care services (Read and Baker, 1996:1)

Other empirical evidence similarly demonstrates that mental health service users experience oppression in areas such as employment, access to health care, and housing (Dunn, 1999; Penn and Wykes, 2003).

Employment

Research shows that only 15 per cent of working-age people with experience of severe mental distress are economically active (Sayce, 2001a) and that "people with mental ill-health have the highest unemployment rate of any group of disabled people in Britain" (Davis and Bird, 2001:13). For example, research in one London borough in 1999 found that 92 per cent of people with long-term experience of mental distress using local community mental health and rehabilitation teams were unemployed (Perkins and Rinaldi, 2002).

It is clear that oppression operates on different dimensions and levels for people with experience of mental distress seeking employment. On the socio-political dimension, systems and structures work to discriminate indirectly against mental health service users, for example in work environments which fail to take into consideration the nature of mental distress which may sometimes make regular attendance difficult. At an individual level, there are many examples of employers directly discriminating against people with a history of mental distress (Lawton-Smith, 2001; Secker et al, 2001)[76]. People have recounted experiences of losing

[76] It is noted that the Disability Discrimination Act 1995 provides the opportunity for people with experience of mental distress to challenge discrimination by employers, and is encouraging people to do so (Grove, 1998). The

their jobs or being refused work, training or education, due to their history of mental distress, and of having to conceal their experiences to keep or secure a job (Dunn, 1999; Read and Baker, 1996). Such experiences are likely to be reinforced by oppression's socio-cultural dimension, with common and erroneous assumptions about people with experience of mental distress being incapable of work, erratic and dangerous to other people (Leff et al, 2000).

Research carried out with 156 service users found that the major perceived barriers to employment and training were: employer attitudes (83%); the benefits system (69%); lack of work experience (54%); and lack of support (53%) (Secker et al, 2001), demonstrating a cycle of lack of opportunity, discrimination, oppression and financial disincentives. Society's refusal to recognise mental health service users' work potential devalues and oppresses them by denying them a productive social role (Grimshaw, 1989).

Unfortunately, health and welfare services are identified as one of the most 'intolerant' groups of employers, with one in five people who reported unfair dismissal from their jobs in Read and Baker's (1996) survey coming from 'caring' professions such as nursing and social work:

> I was employed as a social worker, but after six months I went into hospital with depression. I received no support from my employer and my contract of employment was terminated... (Service user, p.7)

Such findings are surprising in relation to social care professions, given social work's commitment to empowerment and anti-oppressive practice (Parsons et al, 1998). However, the dominance of a biomedical view of 'mental illness' as 'irreversible' within health services may contribute to the reluctance of some health professionals to view 'patients' as competent practitioners.

---

first such case was successful in 1999, when a large construction company admitted unlawful discrimination towards a man with a diagnostic label of 'schizophrenia' from whom they withdrew a job offer on 'medical grounds' (Brindle, 1999). Statistics on the use of the Disability Discrimination Act show that 23 per cent of cases brought under its employment provisions in its first four years of existence involved people with experience of mental distress (Sayce, 2001b), suggesting that oppression of mental health service users by employers is very common but also that increasing numbers of people are resisting such oppression and asserting their citizenship rights.

Treatment by health services

With regard to general health services, half of Read and Baker's (1996) survey respondents felt that they had suffered unfair treatment due to their history of mental distress:

> I went to my GP with a breast lump (and) insisted on a referral to a breast specialist. My GP sent a referral stating 'over-anxious patient, had nervous breakdown at age 17'... I was greeted by the specialist with 'well, you're a bit of a worrier...' (Service user, p.14)

> I moved when I was eight months pregnant and my midwife wrote 'hypomaniac' in large red letters across my notes, even though I had been well for some time. No GP in my new area would take me on. (Service user, p.15)

Such findings highlight the significant power of labels of 'mental illness', particularly in the eyes of health professionals who, both as individuals and as professional groups, accept such labels and the accompanying medical discourse uncritically and who consider such labels to be permanent and irreversible (see p.17). A key element of oppression can be seen in the way in which one particular characteristic, namely experience of mental distress, subsumes someone's identity so that they are forever seen by society as 'a mental patient' rather than as a person with experience of mental distress amongst many other experiences in their lives. Women in MIND (1986) highlight the way in which a label of 'mental illness' once applied affects all further treatment by health professionals:

> ...much of what you have said and done is all recorded in... NHS notes... We are under close supervision *because* we have once been 'mad' by society's definition. I myself do not visit the doctor with my children unless it is really urgent because there is always the risk of being labelled 'neurotic-over-anxious-mother-ex-psychi-patient'. (Service user, p.44-45)[77]

Hence the power over people already held by professionals such as doctors is compounded and amplified for mental health service users in their interactions with general health and social care professionals.

---

[77] Original emphasis.

Housing

Oppression of people with experience of mental distress is also evident in relation to their rights to adequate housing. There have been many, often successful, protests from residents when proposals for local homes for mental health service users were put forward (Campbell and Heginbotham, 1991; Repper and Brooker, 1996). A survey of mental health service providers in England and Wales found that over two-thirds of responding organisations had experienced local opposition to the development of community mental health facilities in the previous five years (Repper et al, 1997). This opposition ranged from protest letters and meetings to direct violence towards service users, staff and property (a key theme of oppression):

> Residents were taunted, beaten up for their benefits, bricks were thrown through windows etc. (Service provider, p.20)
>
> ...there were threats to set fire to the building... there were air pellets fired through one of the windows... (Service provider, p.25)

Respondents reported fear, either for children's safety or of violence, as the reason for this opposition, illustrating oppression's powerful socio-cultural dimension which operates at both an individual and societal level to define people with mental distress as 'dangerous' and essentially 'other' (Stainton, 1998):

> The community was asking things like can you mix mental health provision with mothers and babies. Violence was the focal point... it is to do with dislike and mistrust. These words came up: 'they're not very pleasant', 'we wouldn't have anything in common with them'. (Service provider, p.21)

Read and Baker's (1996) survey found similar evidence of violence towards mental health service users from their neighbours:

> Children have thrown stones at my windows and fruit at me in the street. (Service user, p.4)
>
> Various gangs... call me 'nutter' and spit at me... I am teased and harassed. (Service user, p.4)

Media representations and public attitudes

As Keating (1997) observes, "all our assumptions, stereotypes, biases, myths and notions of otherness and difference come together in cultures of oppression" (p.41). The stigma attached to mental distress is widely known (Gomm, 1996; Hayward and Bright, 1997). The media play a key role in perpetuating this stigma and

reproducing oppression by reinforcing inaccurate cultural stereotypes and fears about mental health service users (Hannigan, 1999; Sayce, 2000; Sieff, 2003). Research has found that such stereotypes are present even in children's media, socialising them to adopt negative attitudes towards people in mental distress from an early age (Wahl, 2003).

An erroneous link is made by both the media and the general public between mental distress and violence (Philo et al, 1996; Pilgrim and Rogers, 2003; Wolff et al, 1996), creating a powerful discourse with serious implications for mental health service users' lives. Although the vast majority of people experiencing mental distress never commit violence (Dunn, 1999), the media gives disproportionate attention to violent incidents committed by mental health service users (Pilgrim and Rogers, 1996). This emphasis contradicts the evidence: a review of Danish mortality data, for example, revealed that people with experience of mental distress were six times more likely to be victims of homicide themselves than was the general population (Hiroeh et al, 2001). Similarly, there was a small reduction in homicides committed by people with experience of mental distress during the 1990s, rather than an increase as suggested by the media (Beresford and Wilson, 2002).

Nonetheless, studies have found that significant numbers of people in Britain view people experiencing mental distress as 'different', unpredictable and potentially dangerous (Leff et al, 2000; Salter and Byrne, 2000), and are reluctant to work and live alongside them (Hannigan, 1999). Indeed, 'mentalism' has been highlighted by Chamberlin (1987) as a specific form of socio-cultural oppression, defined as "a set of assumptions which most people seemed to hold about mental patients: that they were incompetent, unable to do things for themselves, constantly in need of supervision and assistance, unpredictable, likely to be violent or irrational" (p.24). It is clear that such discourse has a powerful social control function, thereby sustaining oppression (Fook, 2002).

Impact of oppression on people with experience of mental distress

This oppression impacts upon the quality of people's lives on psychological, emotional, social and material levels (Barnes et al, 2000; Lundin, 1998; Thesen, 2001).

Psychological and emotional impact

From his research with people with a diagnosis of 'schizophrenia' living in the community, Barham (1997) identifies several ways in which this situation had a psychological impact on participants' lives, including "the pauperization of lives; the cruel effects of stigma...; the barriers to equality with other people, the experience of being made to feel less of a person...; experiences of powerlessness in their efforts to exert some control over their lives, not least in their dealings with the medical profession; and the demoralisation produced by a health and welfare system that treats them as secondary sorts of people or as children" (p.59). These experiences can be seen to echo many of the themes highlighted in earlier discussions of oppression (see p.40), and are compounded by the public's view of 'mental illness' as irrevocably affecting the person diagnosed (as discussed on p.120-121):

> People wonder 'Is he really better, or is he still poorly? Is he OK with the children, is he going to beat them up, is he going to have a fit?' (Service user, p.44)

> I am labelled for the rest of my life... I think schizophrenia will always make me a second-class citizen. I go for an interview for a job and the anxiety builds up... I haven't got a future. (Service user, p.58)

Gomm (1996:81-82) powerfully argues that a range of psychological 'symptoms' commonly attributed to mental health service users, such as 'low self-esteem', 'lack of confidence' and 'paranoia' are often a result of such experiences of oppression. Characteristics such as low self-esteem and a negative outlook on life are identified by Freire (1972) as typical of people who experience 'internalised oppression' (see p.44).

Social and material impact

A range of oppressive material conditions is also experienced by many people with long-term experience of mental distress, including "poverty, poor housing,

homelessness, unemployment or poor opportunities for meaningful, work-related and recreational activities, and lack of a supportive social network and appropriate services" (Oliver et al, 1996:90). For example, of 556 mental health service users surveyed in 2001, 72 per cent were on a low income, 50 per cent felt that this excluded them from their community, and 23 per cent stated that they had been unable to access mental health services on occasions due to financial problems such as paying for transport and childcare (Lawton-Smith, 2001). These conditions can then reinforce prejudiced attitudes held by the general public, contributing to an ongoing relationship between discrimination and social exclusion (Barnes and Shardlow, 1997; Rogers et al, 1993).

Material conditions have a very significant impact on people's quality of life and mental health (Davis and Bird, 2001; Sayce, 2001a), with benefits systems introducing additional stresses and stigmatising treatment (Barnes and Bowl, 2001; Davis, 2003). Sayce (2001a) describes the social exclusion experienced by mental health service users as "the interlocking and mutually compounding problems of impairment, discrimination, diminished social role, lack of economic and social participation and disability" (p.122).

It is clear, therefore, that the powerful interweaving of psychological, socio-cultural and socio-political dimensions of oppression has damaging consequences for mental health service users, who experience such oppression at an individual level, a cultural level in terms of dominant ideologies and social norms, and at a structural level in their interactions with society's institutions. All of these processes of oppression seriously constrain the citizenship rights of people with experience of mental distress.

Citizenship rights of mental health service users

One of Keating's (1997) themes of oppression is "unnecessary restriction or limitations of personal and individual freedom" (p.18). The limited citizenship rights of mental health service users therefore demonstrate oppression experienced by this group (Barnes, 1997a; Sines, 1994).

Mental health service users experience constraints on all three types of citizenship rights: legal and civil rights (to fully participate in the community, such as property and contractual rights, and rights to freedom of speech and of association); political rights (to participate in the community's government, including the right to vote); and social and economic rights (to participate in the community's wellbeing, such as rights to health care, welfare and education) (Barnes and Shardlow, 1997). For example, people detained in British psychiatric hospitals under the Mental Health Act 1983 were, until recently, not allowed to use the hospital's address to register to vote and were thereby prevented from voting if they had no other place of residence at which to register (Rogers and Pilgrim, 1989)[78].

The Human Rights Act 1998, which came into force in 2000, has had some impact on the legally enshrined rights of mental health service users (Sainsbury Centre for Mental Health, 2000)[79]. For example, Article 3 of the Act states that "no one shall be subjected to torture or to inhuman or degrading treatment or punishment", and the European Commission has cited ECT as an example of torture. This right should then give people legal recourse to challenge the use of ECT. The Court of Appeal has indicated in a UK case that forcible treatment imposed on people detained in psychiatric units must be proven to be a medical necessity rather than merely 'beneficial', otherwise it may violate the Act (Mind, 2001b).

With regard to the right to liberty and security (Article 5), however, an exception is made for the lawful detention of "persons of unsound mind, alcoholics or drug addicts or vagrants". It therefore seems that the oppressive practice of compulsory hospitalisation (discussed on p.108-109) will continue to be enshrined in UK legislation.

---

[78] The Labour Government announced the removal of this voting restriction in 1999 via the introduction of its Electoral Reform Bill, ending this source of oppression after hundreds of years (Waugh, 1999).
[79] The Human Rights Act 1998 incorporates the European Convention for the Protection of Human Rights and Fundamental Freedoms into UK domestic law, and makes it unlawful for public authorities to act in any way which is incompatible with the rights guaranteed by this Convention (Leckie and Pickersgill, 1999).

Nonetheless, it is possible that challenges to current psychiatric practice brought under the Act might lead to improvements in policy, service provision, and service culture in the longer term[80].

Mental health policy: the shift from institutional to community care

The shift from institutional to community care, occurring since the 1950s but given impetus by government legislation in the 1990s (Samson, 1995), should have provided an opportunity to develop less oppressive mental health services and to support the social inclusion of mental health service users, as full and equal citizens. This section considers the extent to which this potential has translated into reality.

Community care: a different experience for service users?

The move towards community care can be viewed as having destabilised the biomedical approach to 'mental illness' and therefore the medical profession's monopoly over mental health service users, with more variety in 'treatment' options and professionals involved (Payne, 1996; Samson, 1995). In this way, oppression experienced by mental health service users as a result of psychiatry's practices may have lessened for some people.

Barham (1997:60) found support for the concept of community care from mental health service users but dissatisfaction with the 'care' available in the community (described as "regimes of benign containment"), partly due to its emphasis on medication.

Many people with a history of mental distress living in the community have been identified as segregated and still expected to continue in certain roles as a 'community mental patient' (Barham and Hayward, 1996; Brandon, 1991):

---

[80] Examples of such challenges include a 2002 test case of seven detained psychiatric inpatients, when it was ruled that Article 5(4) of the Human Rights Act (Macgregor-Morris et al, 2001) had been breached due to services' failure to provide them with speedy Mental Health Tribunal reviews (Mind, 2002b). Similarly, women may be able to challenge their placement on mixed-sex wards under Article 8, which gives the right of respect for peoples' private lives (Inyama, 2001).

> 'Safe havens' (such as friends' houses and pubs) characterise the postinstitutional worlds of many ex-patients, rather than acceptance and inclusion by wider community networks and support systems. (Rogers and Pilgrim, 2003:56)

As discussed earlier, this 'othering' of people with experience of mental distress contributes to and is used to justify their continuing marginalisation in society. Indeed, it could be argued that "the life chances of some people with mental illness have if anything been degraded still further" (Barham, 1997:104) by the move into the community, with many people shifting to the identity of 'pauper mental patient' due to problems with housing and employment (discussed earlier).

Community living cannot alleviate the segregation experienced in institutional care while people continue to be excluded from meaningful employment and activity, and therefore live in poverty and isolation (Dodd, 1998; Grimshaw, 1989). In this sense, many mental health service users have been identified as "in the community but not of the community" (Campbell, 1999a:16).

'Coercion in the community'

Concern has also been expressed at the apparent extension of psychiatric surveillance and compulsion into the community in the UK (Manning and Shaw, 1999; Pilgrim and Waldron, 1998), resulting from the Government's push to 'protect the public' from 'risk' (Langan and Lindow, 2004) in the light of a small number of highly publicised violent acts committed by people experiencing mental distress living in the community (Beresford, 2000; Davis, 2002).

Such surveillance can be seen as part of Foucault's 'carceral society' (1977), extending the exercise of disciplinary power beyond psychiatric institutions into general society to achieve "a generalized surveillance" (p.209) of mental health service users (see p.57-58). As Foucault suggests, people's awareness that they are being monitored and assessed in the community, with the threat of becoming subject to 'supervision' and 'constraint' procedures (such as community treatment orders, supervised discharge orders and supervision registers) is likely to ensure that people regulate their own behaviour to avoid being 'punished' in this way.

The introduction of compulsory treatment in the community would be likely to maintain psychiatry's dominance of community mental health services (Barham, 1997) and to reinforce the medical discourse of 'mental illness'. The development of assertive outreach teams, which use more aggressive methods to support 'hard to reach' service users and ensure compliance with treatment, also places other community mental health professionals in stronger policing and social control roles (Davis, 2002), thereby enhancing their state-legitimated 'power over' people in mental distress.

These moves towards greater control of people with experience of mental distress in the community reinforce their social exclusion (Rogers and Pilgrim, 2003) and contradict the Government's policy emphasis on citizenship and user empowerment (Beresford and Wilson, 2002; Campbell, 1999a).

In this respect, then, action by the British mental health user/survivor movement to secure full citizenship rights and to challenge oppression remains critical in counteracting such developments. This action is considered in the next section, in the context of strategies for empowerment.

Strategies for empowerment and people experiencing mental distress

Due to mental health service users' diversity of experiences, there is likely to be corresponding diversity in strategies for empowerment in which people choose to engage (Barnes and Bowl, 2001:68). Indeed, empirical evidence shows that British mental health service users/survivors are using a wide range of strategies for empowerment, both individually and collectively, and within and outside statutory service systems. These strategies aim for both consumerist and liberational forms of empowerment (as discussed in Chapter Three).

The British user/survivor movement and strategies for empowerment

Many groups of mental health service users/survivors are now established in the UK, at both national and local levels, and these groups are generally considered to form the UK user/survivor movement (Barnes and Bowl, 2001; Campbell, 1999b). A

common identity for people involved in the movement is their shared experience of oppression, often via mental health services. The user/survivor movement exists to counteract this oppression and the corresponding powerlessness and discrimination (Survivors Speak Out, 1988), and to "put value back" into people's experiences of distress (O'Hagan, 1993:5). For this reason, 'consciousness-raising' is seen as a vital activity in which people engage (Peck and Barker, 1997; Wallcraft, 1994), "to continue to tell each other our stories so we know what we have in common, and that it is possible to rise above the oppression experienced as a psychiatric patient" (Lindow, 1999:213).

User groups involved in the UK movement have similar aims and values, working to support people and validate experiences, change services, challenge the medicalisation of distress (Barnes, 1999a; Beresford, 2001b), secure citizenship rights (Barnes and Shardlow, 1997; Beresford, 1997) and confront societal oppression and prejudice (Barnes and Wistow, 1994; Kumar, 2000). These aims are congruent with the liberational model of empowerment (see p.81).

Nonetheless, strategies for both consumerist and liberational empowerment have been used within the movement depending on people's needs and priorities (Brandon, 1995b; Dickerson, 1998; Morgan, 1993). These strategies include: self-help and mutual support; self-advocacy; consciousness-raising; campaigning and politics; developing alternative services; research and training; joint working (with service providers, planners and policy makers); and using the market, for example trying to influence service contracts (Crawford, 2001; Hogg, 1999; Schafer, 1996).

User/survivor groups and organisations

'Sites of action' inside and outside the statutory service systems have been identified by Barnes and Bowl (2001) as ways in which UK mental health service users are adopting strategies for empowerment. These sites include action within voluntary organisations (such as Mind and Rethink's[81] service user networks), and via separate national user organisations (for example Survivors Speak Out, the United Kingdom Advocacy Network, and the Hearing Voices Network). It has been suggested that

[81] Previously known as the National Schizophrenia Fellowship.

these separately organised national groups are aiming for empowerment at individual, group, organisational and societal levels (as highlighted on p.86) (Barnes and Bowl, 2001:49).

Many local service user groups also exist, including self-help groups, survivor-only groups, advocacy projects, patients' councils, and user forums working to change services (Read and Wallcraft, 1992).

Empowerment is defined in Chapter Three as an ongoing process of personal growth and development (see p.105). It is clear that groups of service users/survivors can help to facilitate such personal development in a range of ways. User groups are beneficial in developing people's skills and confidence (Barnes et al, 1999; Davey, 1999). The expression of voice is important in these groups' activities, via advocacy, campaigning and lobbying (Barnes and Bowl, 2001). Collective organisation is also vital, "as a means of enabling personal support and development..., as a source of increased legitimacy through expressing collective views, and as a forum in which experiential knowledge could be articulated and valued" (Barnes and Bowl, 2001:50)[82].

Individual and collective self-advocacy is a major activity engaged in by user groups, defined as "people speaking *for themselves* and asserting their own rights" (Beresford and Croft, 1993:86)[83]. Collective self-advocacy is seen as an important way of challenging the psychiatric system (Campbell, 1999b; Mind, 1992).

A potential tension exists with regard to mental health professionals' involvement in survivor groups, as they are viewed by many as playing a key role in the disempowerment which users/survivors are challenging (Campbell, 1990)[84]. Nonetheless, alliances with workers can provide groups with access to skills,

---

[82] In light of the multiple oppression experienced (as discussed above), specific groups such as women and Black and minority ethnic groups have also campaigned within the user/survivor movement to highlight particular issues, and have organised separately to provide mutual support and undertake campaigning (Barnes and Bowl, 2001).

[83] Original emphasis.

[84] The extent to which user/survivor groups involve professional workers as allies is an ongoing theme within the movement (Ferguson, 1997; Kumar, 2000), with some groups accepting professionals as allies and others refusing to work with them, and with some groups accepting the medical model of 'mental illness' and authority of mental health professionals (Barnes, 1997).

knowledge and practical support (Bowl, 1996; Campbell, 1990). In this way, professionals can work to support people to develop their own power both personally and collectively (see p.84).

Separate organisation of service users is also fostering the development of alternative explanations of psychological distress, for example via the Hearing Voices network, as another strategy for empowerment (thus challenging the dominant medical discourse of 'mental illness'). This work has taken place within the context both of self-help activities and of user-led research.

Another example of users/survivors working to redefine perceptions of mental distress is the growing recovery movement (see p.91), which challenges the idea that people can never recover from mental distress and disseminates self-management strategies (Baker and Strong, 2001; Frese and Davis, 1997; Mead and Copeland, 2000). The recovery approach is clearly a strategy for liberational empowerment, focused on overcoming oppression to enable people to play full and active roles as equal citizens.

Research and education

User involvement in research and education are two strategies for empowerment which are growing in popularity amongst service users (Beresford, 2001b; Lindow, 2001; Thornicroft et al, 2002), government (Department of Health, 2001b) and academics (Barnes and Warren, 1999; Hogg, 1999; Wykes, 2003), possibly due to different agendas. Beresford (2002b) draws an important philosophical distinction between the kind of user involvement in research advocated by the government and statutory organisations and that promoted by user organisations, corresponding to consumerist and democratic models of involvement (see p.97):

> While mainstream interest in user involvement in research and evaluation highlights feeding user knowledge and experience into existing research arrangements and paradigms, service users and their organisations emphasise the transformation of research philosophy, production social relations *(sic)*, and objectives. (p.101-102)

The user/survivor movement agenda in advocating user-led and user-controlled research is clearly to develop new discourses of mental distress (resurrecting 'local, subjugated knowledges') (Foucault, 1980), to challenge professional power in

defining people's needs, problems and solutions, and to confront the oppressive cultural view of mental health service users as 'lacking insight' and 'incapable' of undertaking research[85].

Traditional approaches to research have been extensively criticised by service users for being alienating and oppressive, and for having failed to improve people's lives (Oliver, 1993). Calls have been made for a fundamental change in the social relations of research production (Oliver, 1992; Zarb, 1992), to involve people who have traditionally been research 'subjects' far more actively in the research process (discussed further in Chapter Five).

To encourage shifts in professional attitudes and practice (again challenging professional power and the oppressive view of people in mental distress as 'other'), service user involvement in education and training for health and social care professionals is also advocated (Curran, 1997; Department of Health, 2000b), ideally as core trainers and advisers rather than 'one-off' presenters (Crawford, 2001)[86]. There is limited research evidence to date on the impact of user involvement in training mental health professionals (Campbell, 2001), although a small research project with mental health nursing students found that:

> ...students who were given an experience of user involvement in classroom work... were less likely to rely on... professional terminology and jargon, more able to empathise with clients' distressing experiences, less likely to use defensive 'distancing' and more likely to take an individualised approach to assessment... (Wood and Wilson-Barnett, 1999:257)

Hence, in addition to the potentially empowering and validating experience for service users being enabled to describe their experiences to future professionals and to challenge professional conceptualisations of distress, this research suggests that there may also be positive outcomes in terms of less oppressive and more empathic professional practice.

---

[85] Research, both funded and unfunded, has been undertaken by individual users/survivors (Beresford and Wallcraft, 1997), and many organisations also involve users as researchers (for example, the Sainsbury Centre for Mental Health's 'Users' Voices' Project [Rose D., 2001b], and the Mental Health Foundation's 'Strategies for Living' Project [Mental Health Foundation, 1997; Nicholls, 2001]). Several networks promoting user-led mental health research exist, including the Survivor Researchers Network (Beresford, 2002b), Folk.us (The Forum for Collaboration with Users in Research) in South West England, and SURESearch, in the West Midlands.

[86] Service users are being asked to teach on qualifying and post-qualifying professional courses at universities (Campbell, 1999b; Evans, 1996), and to have an input into curriculum design (Fraher and Limpinnian, 1999).

Beyond this involvement, survivors argue for the employment of more mental health service users and ex-users as mental health professionals (Campbell, 1999a), due to their ability to empathise, give practical advice and insight, and act as role models (Dickerson, 1998; Frese and Davis, 1997). This strategy for empowerment can be seen to alter (although not remove) the power imbalance inherent in the traditional professional/service user relationship and to challenge the view of service users as passive and incapable of taking on productive roles within society.

User involvement in service planning and delivery

In addition to activities outside the statutory system, opportunities for service users to become involved in public service decision-making are increasingly available as a result of policy developments, and there now exists widespread acceptance that service users have valuable contributions to make to mental health service development (Beresford et al, 2000).

Individuals' involvement in their care and treatment is now encouraged more, for example via user-led needs assessment (Le Grand and Kessler, 1996), access to advocates (Henderson and Pochin, 2001) and greater provision of information (Campbell, 2001). Collective user involvement in service planning and development is also advocated in government policy. Although this involvement still tends to be limited to consumerist notions adhering to a 'top-down' government-imposed agenda, it can nonetheless be seen as a strategy for empowerment by aiming to alter the nature of traditionally disempowering service provision both with regard to service outcomes and professional behaviour (Beresford et al, 2000).

Concern has been raised that while policy makers and managers are enthusiastic about user involvement, many professionals are more resistant (Campbell, 2001; Crawford, 2001; Peck and Barker, 1997), particularly when involvement extends to service users offering their own interpretations of distress (Campbell, 1999b). Further, professionals may view user involvement as having primarily therapeutic goals for individuals rather than broader goals of political and social change, or even of change within the mental health system (Barnes and Bowl, 2001). This clearly relates to professionals' discomfort with challenges to their long-held power and legitimacy, as user interpretations of distress and corresponding support threaten to

undermine the very basis of professions built around a medical model of 'mental illness'.

Some authors caution against user groups responding to statutory services' agendas (Beresford et al, 2000; Evans, 1996; Rose D., 2001a). Power imbalances, and differences between the agendas of statutory services and user organisations (Wright, 1999) can lead to involvement being of limited benefit to user groups (Campbell, 2001), particularly if working towards liberational empowerment. For these reasons, it can be argued that involvement in 'top-down' service-defined activities is likely to be less empowering for user groups than pursuing their own agendas via 'bottom-up' drives for increased user involvement and empowerment (Barnes and Bowl, 2001:105).

At the least, a 'twin-track' approach to user involvement and empowerment is advocated, with service users working both within statutory organisations to maximise their influence on services (thereby working towards consumerist empowerment) and outside organisations to campaign for broader change and thereby work towards liberational empowerment (Croft and Beresford, 1995).

This exploration of the range of sites of action occupied by mental health service users/survivors highlights some of the strategies for empowerment used, as well as constraints on these strategies. However, to understand the context within which these sites of action have developed, it is also important to explore British government policy on user involvement and empowerment.

Parallel development of policy context

Opportunities for service users to have a voice within the British statutory service system began to occur in parallel with developments in user movements in the 1980s (Barnes and Bowl, 2001). These opportunities stemmed first from Conservative neo-liberal ideas about 'markets' and listening to 'consumers', and then from Labour's notions of 'partnership' (Barker et al, 1999; Calnan and Gabe, 2001) and 'social inclusion'.

Health and social care policy

The British Conservative governments of the 1980s and 1990s introduced NHS reforms which emphasised greater user involvement (Peck and Barker, 1997), for example in assessment and the production of community care plans (Braye, 2000) and in health authority decision-making processes (Department of Health, 1992). The White Paper 'Working for Patients' (Department of Health, 1989) and the resulting NHS and Community Care Act 1990 introduced managerialism and quasi-markets into the health service.

This 'top-down' drive for user involvement was underpinned by the view of the user as consumer (see p.97-98), to make services more responsive and efficient (Calnan and Gabe, 2001). The emphasis of these reforms was on consumer empowerment via the 'exit' approach rather than the 'voice' approach (Hoyes et al, 1993).

Patient's Charters were also published, including one for mental health services (Department of Health, 1996a), which again propounded a consumerist model of involvement emphasising information provision and treatment choices (p.3).

These early attempts to encourage user involvement were criticised for assuming that introducing legislation would be sufficient to induce a culture shift to user-centred practice (Barnes and Bowl, 2001). The very concept of the user as consumer was criticised by many commentators, who argued that service users were not necessarily able to 'shop around' for health care (Calnan and Gabe, 2001), and that providing people with choice in positions of uncertainty and lack of information might be disempowering (Barnes and Prior, 1996). Further criticism has been levelled that such a consumerist approach was not primarily concerned with user empowerment (Schafer, 1996), but rather with limiting the power of professionals (Barnes et al, 1999) and enabling the government to exert central control over NHS Trusts' performance (Crinson, 1998).

Nevertheless, although the Conservative government's 'top-down' consumerist approach did not accord with the emancipatory philosophy of the user movement, it did open up opportunities for service users to have greater influence within the health and social care service system (Evans, 1996; Pilgrim and Waldron, 1998) by

"creating an environment in which it was hard for officials to dismiss user views" (Barnes et al, 1999:81).

When the Labour government came into power in 1997, they continued to emphasise user involvement in health and social care service planning and delivery, but with a professed commitment to partnership working rather than consumerism. In social care, the Best Value initiative (Department of the Environment, Transport and the Regions, 1998) placed a duty on local authorities to consult with local communities to ensure user-centred service provision. Commitment to greater public involvement and working in partnership with other agencies and local communities was apparent in both the 1997 and 1999 White Papers on health (Department of Health, 1997, 1999a) and in the government's guide to patient involvement (Department of Health, 1999b).

Both 1999 policy documents emphasised health inequalities and their structural origins, representing a shift in official government discourse away from a medical model of illness towards an acknowledgement of the influence of social, economic and environmental conditions on health (Barnes and Bowl, 2001), and thereby opening up possibilities for strategies targeted at addressing mental health service users' social and economic circumstances (an important element of liberational empowerment).

Nonetheless, the Conservatives' emphasis on consumerism could still be detected in Labour's major NHS policy guidance (Gilliatt et al, 2000; Shaw, 1999). The NHS Plan (Department of Health, 2000a), for example, advocated a consumerist approach to involvement, stating that patients' say in the NHS would be increased by providing them with better information and proper redress, introducing a new NHS Charter to replace the Patient's Charter, and by conducting regular patients' surveys to make services more responsive. All of these activities are located at the information/consultation end of the involvement continuum (see p.99).

The NHS Plan also announced an intention to increase both 'patient' and 'citizen' participation in a range of health service decision-making structures[87]. The government described this raft of initiatives as "citizens empowerment mechanisms" (Department of Health, 2000a:95), although such participation was only likely to be empowering if located towards the top of Arnstein's (1969) ladder (see p.101).

A theme initiated by the Conservative government and continued by the Labour government was that of user involvement in health and social care research. To this end, a Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme was established in 1996. This group later became Consumers in NHS Research (1999)[88], which advocated an active role for NHS 'consumers'[89] in "commissioning and undertaking research, interpreting the results, and disseminating and implementing the findings" (p.1). In social care, the Social Care Institute for Excellence (SCIE), established in 2001 to identify valuable research, information and examples of good practice, also committed to having a service user focus, promoting empowerment and change, and encouraging user participation. The Labour government's Research Governance Framework for Health and Social Care (Department of Health, 2001b) states that "participants or their representatives should be involved wherever possible in the design, conduct, analysis and reporting of research" (p.11).

In 2002, the British government launched the National Institute for Mental Health in England (NIMHE), an organisation intended to lead changes in mental health services. NIMHE includes a Mental Health Research Network, which promises that "service users and carers will have a central role in developing, governing, delivering and evaluating the research programme of NIMHE" (Department of Health, 2002a:2).

---

[87] These included patients' forums, local advisory forums, and increased citizen and lay involvement in professional regulatory bodies, the new NHS Modernisation Board, and the National Institute for Clinical Excellence (via a Citizens Council). Further initiatives included the establishment of a Commission for Patient and Public Involvement in Health (CPPIH) in 2003, and the replacement of Community Health Councils with Patient and Public Involvement Forums.

[88] Consumers in NHS Research have now been renamed as INVOLVE (in acknowledgement of the particular connotations of the word 'consumer', and of the group's broader remit in encompassing public health and social care research and development).

[89] Defined as patients, carers, user groups and voluntary organisations.

Hence the government is advocating a role for users not only as advisory members on research committees but also as active researchers involved throughout the research process. Nonetheless, it has been cautioned that this 'official' emphasis on user involvement in research has been more concerned with the practicalities i.e. 'how' to involve users in research (Beresford, 2002b) than with the underpinning philosophy i.e. 'why' do so.

In addition to general health and social care policy, exploration of specific mental health policy reveals a more radical government view of user involvement.

Mental health policy

In 1996, the Conservative government produced 'Building Bridges', inter-agency guidance which outlined a commitment to user involvement in mental health service planning and delivery at both an individual and strategic level with statements such as "the key to sensitive and appropriate services is proper consultation with users" (Department of Health, 1996b:10). The equation here with consultation suggests a conception of involvement which accords service users very little power (see p.99).

Soon after its election in 1997, the Labour government announced mental health as a top health priority, and produced major guidance in the form of 'Modernising Mental Health Services' (Department of Health, 1998). This guidance included a commitment to involving service users "in the process of treatment and care" (p.47), a very limited decision-making role (Barnes and Bowl, 2001).

The National Service Framework for Mental Health (Department of Health, 1999c) continued with the same consumerist model of user involvement, and was similarly criticised for not giving enough emphasis to user involvement and user perspectives (Sainsbury Centre for Mental Health, 1999).

Nonetheless, the National Service Framework recognised the link between a diagnosis of 'mental illness' and social exclusion, making a commitment to "combat discrimination against individuals and groups with mental health problems, and promote their social inclusion" (Department of Health, 1999c:14). The government's vision for mental health care, 'The Journey to Recovery', continued

this emphasis, aiming to "involve and include people with mental health problems as equal citizens in society" (Department of Health, 2001a). Its pledge to "work against social exclusion and marginalization" (p.12) and to reduce stigma and discrimination indicates a shift in mental health policy discourse away from the user as consumer to the user as citizen, further illustrated in its statement that:

> Greater opportunities will also be sought for people with mental health problems to access suitable housing, education, welfare benefits and other services, to help empower them to participate in society. (Department of Health, 2001a:12)

This acknowledges that service users' social circumstances, including their level of income, play a key role in empowerment and recovery (Rogers et al, 1993).

In June 2004, the British government launched a comprehensive report on mental health and social exclusion (Office of the Deputy Prime Minister, 2004)[90], which calls for a major cultural shift in attitudes towards mental health service users. The report highlights the negative impact of stigma and discrimination, and emphasises the need to promote social inclusion by facilitating access to mainstream opportunities for mental health service users in relation to employment, housing, education, financial and legal issues, family needs, transport, and community participation. A detailed action plan with targets is included in the report, involving many government departments and national agencies.

This report appears to represent the first concerted attempt by a British government to comprehensively address mental health service users' social needs and the consequences of oppression and discrimination, acknowledging people's rights to participate as full citizens in society. Other work by the government in recent years further recognises multiple oppression experienced by some people using mental health services[91].

Some recognition of the importance of social models of distress (see p.18) is also occurring in government agencies. For example, Topps England (the strategic

---

[90] Evidence for this report was gathered via extensive consultation with mental health service users, carers and agencies, literature reviews and case study research.

[91] For example its strategy on women and mental health (Department of Health, 2002c) and its report on mental health services for Black and minority ethnic communities (NIMHE, 2003).

workforce development body for social care) is supporting the Social Perspectives Network for Modern Mental Health, established in 2002 to promote social models of distress and to encourage their integration into social care service systems. Similarly, the NIMHE declares itself to be committed to a 'disability inclusion model' for mental health and to working closely with the Disability Rights Commission.

In relation to mental health, therefore, the government now appears to be supporting the liberational model of empowerment developed by civil rights and user movements, rather than its earlier consumerist approach. This development is interesting, as general health and social care policy continues to propose a consumerist model. It is possible that the more liberational emphasis in mental health policy has been influenced by campaigning by the user/survivor movement and national mental health organisations.

However, the Labour government's proposed reform of current mental health legislation (Department of Health, 1999d, 2002b; Department of Health and Home Office, 2000) appears to contradict such developments and has caused great alarm amongst both service users and some professionals (e.g. Zigmond, 2001). A shift towards more restrictive and prescriptive legislation indicative of Foucault's (1977) 'carceral society' (see p.58) has occurred (Beresford, 2001b; Peck and Barker, 1997). Significant user representations have been unable to prevent the government from proceeding with proposals for compulsory community treatment and indefinite detention of 'personality disordered' people considered to be 'untreatable' (Campbell, 1999b), leading some survivors to suggest that the movement's involvement in policy development has been "minimal or tokenistic" (Beresford, 2000:168)[92].

---

[92] Indeed, it has been suggested that although it would now seem difficult to pursue a major national mental health policy development without involving service users, this does not necessarily mean that those service users have power within the decision-making context (Barnes and Bowl, 2001). For example, the Department of Health national working group set up in 1998 to draw up the National Service Framework for Mental Health included service users, but these users resigned when they realised that the government's policy developments would include forced compliance with medication in the community (Barnes and Bowl, 2001).

With regard to the extent to which government policy has facilitated strategies for empowerment for mental health service users, a contradictory position is therefore apparent. User involvement in statutory service planning based on consumerist notions of information-giving and consultation adhering to a government-imposed agenda is unlikely to be experienced as empowering for service users. However, legislative requirements for user involvement have provided opportunities for mental health service users to influence statutory systems and to work to develop more participative involvement opportunities. If involvement initiatives which accord service users more control and power can be developed within statutory services, opportunities for a more liberational form of empowerment may increase.

Current government mental health policy discourse echoes the user/survivor movement's own discourse of improving citizenship, promoting recovery and combating discrimination and social exclusion, and as such could be viewed as facilitating service users' strategies for liberational empowerment. However, there appears to be a certain 'lack of fit' between this official discourse and policy implementation. Furthermore, restrictive legislation is a source of disempowerment for service users (Newbigging, 2001; Peck and Barker, 1997) and may deter some user groups from pursuing close collaboration and involvement with statutory organisations (Campbell, 2001).

Conclusion

Mental health service users as an oppressed group

As explored in Chapter Two, Keating's (1997) integrated model of oppression is valuable in demonstrating the dimensions of oppression and the levels at which it operates. Throughout this chapter, attention has been drawn to ways in which this model can be applied to empirical evidence to support the argument that mental health service users can be defined as an oppressed group (Barnes and Wistow, 1994; Brandon, 1995a).

The psychological dimension of oppression is evident in the disrespectful and dehumanising treatment by both mental health and general health professionals described by service users, and in the highlighted hostility, abuse and harassment

from neighbours. Psychological oppression is compounded for people who simultaneously experience other forms of oppression such as racism (see p.114-116). The 'internalised oppression' that Freire (1972) identified amongst marginalised people is also apparent in service user accounts of low self-esteem, negative outlooks on life, lack of confidence and feeling 'less of a person' due to a diagnosis of 'mental illness'.

The socio-cultural dimension of oppression is strongly evident in research findings that the general public do not want to work or live alongside mental health service users (Hannigan, 1999). Prevailing scientific 'discourses of truth' (Foucault, 1980) define people in mental distress as biologically inferior and therefore in need of lifelong medical intervention, and dangerous and in need of containment and control rather than of meaningful work opportunities and social relationships. Such (mis)conceptions are heavily reinforced and perpetuated by the media in their treatment of stories about people with experience of mental distress. The view of medicine as the only legitimate way to 'diagnose' and 'treat' mental distress is also heavily embedded in British social values, and contributes to the oppression experienced by mental health service users via psychiatry.

With regard to the socio-political dimension of oppression, evidence presented has demonstrated that people with experience of mental distress encounter such oppression from a range of society's institutions (see p.117), including psychiatry. The political institutions of government legitimise such oppressive treatment by the legal powers which they give to mental health professionals and by the predominant role which they accord to psychiatry in policy development.

With regard to the nature of power, the links between knowledge and power identified by Foucault are evident throughout this chapter, for example in service users' accounts of the dominant use of physical treatments by doctors. Foucault's disciplinary power clearly operates for mental health service users in both inpatient and community settings, and as such has been found to be of significant relevance to this research.

These frameworks for understanding oppression and power have therefore been shown to illuminate experiences of mental health service users recounted in the literature, and will subsequently be used to explore findings from the primary research undertaken for this dissertation.

A central tenet of this doctoral work is that the oppression of people with experience of mental distress may be at least partly countered by strategies of empowerment, involvement and participation.

Linking strategies and levels of empowerment

The UK user/survivor movement goes beyond working to achieve consumerist empowerment to focus on the liberational model of empowerment: "their objectives are explicitly concerned with the relationship between people who use mental health services, the communities in which they live, and the state" (Barnes and Bowl, 2001:66).

British governments' 'top-down' user involvement policy initiatives during the 1980s and 1990s tended to support the consumerist model of empowerment, although more recent mental health policy has at least employed the rhetoric of the liberational model with its emphasis on challenging discrimination and encouraging full citizenship for marginalised groups.

Empowerment can be identified at individual, group, organisational and structural levels (see p.86), reflecting the range of levels and dimensions on which oppression operates. These levels are likely to influence the range of strategies adopted (Barnes and Bowl, 2001). For example, the user/survivor movement's activities in validating individuals' experiences and providing opportunities for the development of skills and confidence are clearly strategies for individual empowerment, which in turn contribute to group empowerment.

Strategies for empowerment to counter socio-cultural oppression are evident in user groups' attempts to challenge the medicalisation of their distress, define alternative ways of conceptualising and dealing with distress (see p.130), alter media portrayals

of distress, and influence professional perceptions of mental health service users, via campaigning, research, education and training.

The user/survivor movement has focused considerable effort on achieving changes within the mental health system as a strategy for organisational empowerment. Such work within mental health services is critically important due to the significant role these play in users' lives and due to their influence on public perceptions of mental health service users. In this respect, working with professionals to transform their practice can be justified as an empowering strategy for mental health service users (Barnes and Bowl, 2001). If such user involvement work is to be empowering in the liberational sense, work is needed which aims towards the maximum ends of the involvement continuum (p.99) and participation ladder (p.101), rather than at the minimum end of consultation and information-giving as does much work in the consumerist vein.

It has been suggested that the UK user/survivor movement has been least successful in working towards empowerment at a community or structural level, unlike the UK disability movement. For example, the disability movement, strongly located in the social model of disability (see p.33), has argued that a strategy for liberational empowerment would be to give disabled people the money to be able to purchase care for themselves, which has paved the way for direct payments legislation intended to facilitate such empowerment (Beresford et al, 2000; Morris, 1997).

It is important to note that a quarter of all cases supported by the Disability Rights Commission in its first year of existence (2000/01) were cases for mental health service users, as government policy includes mental health service users in disability legislation, demonstrating that "the overall disability rights framework has the potential to make a difference to the life opportunities of mental health user/survivors" (Sayce, 2001b:28).

Survivors have argued that the user/survivor movement would benefit in its action for empowerment from broadening its focus from mental health services to build alliances with other oppressed groups focused on civil rights issues, such as organisations of disabled people and Black and minority ethnic groups (Campbell,

2001), and have called for "inclusivity and co-operation... as bases for effective common action and resistance" (Beresford, 2000:171). Moves to build links between such movements are therefore likely to strengthen mental health service users' strategies for community or structural empowerment in the liberational sense.

The following chapter provides more detail on one of the strategies for empowerment highlighted, namely that of service users conducting research, in the context of exposition of the research methodology developed for this doctoral work.

Chapter Five: Research Methodology

Introduction

This chapter explores the choice of an appropriate research methodology for working with people with experience of mental distress, with reference to social science research paradigms and corresponding epistemological and theoretical perspectives. The choice of methods is described in the following chapter, on research design.

The first section examines three paradigms underpinning social science research, the positivist, interpretative and emancipatory paradigms, and their relationship to different forms of knowledge and inquiry. It is suggested that any exploration of research methodology should be underpinned by consideration of a researcher's paradigmatic standpoint. In the light of criticisms of both positivist and interpretative approaches for the oppressive social relations of research production they entail, emancipatory research (ER) is proposed as a form of inquiry which aims to challenge oppression, give control of research production to participants, and reject neutrality in favour of political commitment. In line with the ER approach, the second section of this chapter highlights the way in which my own biography and values have framed my approach to this research project.

The third section explores participatory research (PR) as a form of emancipatory inquiry, including discussion of its diverse origins, varying levels of participation in research, and potential issues and tensions in undertaking PR. On the basis of this evidence, it is concluded in the fourth section that PR holds potential as a strategy for empowerment for participants involved in this process.

Ontology, epistemology, theoretical perspectives and methodology

It is important to be clear about the meaning of the term 'research methodology', and the related concepts of ontology, epistemology and theoretical perspective(s)

informing methodology. Crotty's (1998) helpful definitions of these concepts, each of which informs the next[93], are provided in Table 4.

Table 4: Key elements of research process

Concept	Description
Ontology	The study of the nature of existence and the structure of reality, which sits alongside epistemology in informing the theoretical perspective
Epistemology	The theory of knowledge (and therefore of the relationship between the 'researcher' and the 'researched') embedded in the theoretical perspective and thereby in the methodology
Theoretical perspective	The philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria
Methodology	The strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes
Methods	The techniques or procedures used to gather and analyse data related to some research question or hypothesis

(Source: Crotty, 1998: 3 and 10)

It is clear that all researchers bring their own theoretical assumptions, world views and values to their choice of methodology (Carspecken and Apple, 1992; Rappaport, 1994), based upon personal biography, life experiences and prior learning (Creswell, 1998; Denzin and Lincoln, 1998). It is important that researchers explicitly state the theoretical perspectives to which they adhere when discussing their methodological decisions (Crotty, 1998). This chapter therefore describes the epistemological and theoretical influences on my choice of research methodology for this doctoral work, framed by my own personal world view. To contextualise this exposition, however, it is first important to critically explore possible research approaches, termed research 'paradigms'.

[93] For example, realism (ontology) informs objectivism (an epistemological perspective), which in turn informs the theoretical perspective of positivism, influencing the choice of survey research as a methodology, and correspondingly of questionnaires as an appropriate method (Crotty, 1998).

The nature of paradigms

Kuhn's (1970) sociological definition of a paradigm is "the entire constellation of beliefs, values, techniques, and so on shared by the members of a given community" (p.175). Guba and Lincoln (1989) emphasise belief as a key characteristic of paradigms; in that "they cannot be proven or disproven, but they represent the most fundamental positions we are willing to take" (p.80). In this definition, therefore, paradigms correspond to Crotty's (1998) conceptualisation of theoretical perspectives (see p.146).

Maguire (1987:11) argues that paradigms play a powerful role in the academic pursuit of knowledge, shaping the way in which disciplines define and research issues. Kuhn (1970) suggests that revolutions can be identified in the history of science when existing traditions of scientific practice throw up too many anomalies and become destabilised, such that a 'paradigm shift' occurs and scientists are led to a new set of values and beliefs to underpin their practice. Such a paradigm shift will result in changes in both the theory and methods viewed as legitimate.

It is acknowledged that paradigms underpinning methodological approaches should not necessarily be considered to be in some form of hierarchy or competition, in that "in a postmodern world where boundaries... are being challenged... all claims to truth are historical and cultural constructs and all need to be examined in that light" (Humphries, 1997:para. 2.10). Nonetheless, a range of social science paradigms has been identified, each implying distinctive ways of understanding and researching the social world, and it is helpful to review their defining characteristics in order to locate this doctoral work.

Paradigms and forms of knowledge in social research

New paradigms have emerged within social science and social research as the traditionally 'dominant' paradigm, referred to as positivism, has increasingly been challenged (Lather, 1992; Oliver, 1992; Reason and Rowan, 1981a).

The existence of various theoretical perspectives or paradigms has been linked to Habermas' (1972) typology of knowledge. Habermas identifies three kinds of "knowledge-constitutive human interests" (p.311) via which people define their realities and experiences. These types of interests are labelled technical, practical and emancipatory, and correspond to different forms of scientific inquiry (p.308). Hence, technical or instrumental knowledge results from empirical-analytic inquiry, which focuses on *predicting* laws and theories from observable social behaviour. In contrast, practical knowledge is seen to come from hermeneutic or cultural inquiry, which emphasises *understanding* human interaction and its meaning within different social systems rather than producing generalisable laws about human behaviour.

Emancipatory knowledge, Habermas' third form, arises from self-reflective critical inquiry which recognises power's central role in social relationships and aims to act upon power imbalances in social systems. Maguire (1987) argues that this emphasis on power marks a key difference between emancipatory, critical knowledge, and technical and practical forms of knowledge, which tend to ignore the role of power in political, economic and social structures.

Lather (1992) categorises forms of inquiry (namely a combination of theoretical perspectives and methodologies) according to the purpose for which the knowledge produced is intended, summarised in Table 5:

Table 5: Forms of inquiry and purpose of knowledge produced

Prediction	Understanding	Emancipation
• positivism	• interpretative	• critical
	• naturalistic	• neo-Marxist
	• constructivist	• feminist
	• phenomenological	• race-specific
	• hermeneutic	• praxis-oriented
	• symbolic interaction	• Freirean
	• microethnography	• participatory

(Source: Lather, 1992:89)

The above categorisation is useful in locating existing social research paradigms within three traditions[94], broadly characterised as positivist, interpretative and emancipatory (Oliver, 1992). It is valuable to examine each of these groupings in turn, and in relation to one another, when choosing which research methodology might be most appropriate for working with oppressed groups such as mental health service users[95]. Denzin and Lincoln (1998) define paradigms as "overarching philosophical systems denoting particular ontologies, epistemologies, and methodologies" (p.4), and therefore the following discussion will highlight the ontological, epistemological and methodological perspective of each paradigm.

Positivism: the traditional 'scientific' paradigm

Positivism, identified by Lather (1992) as "supposedly a transhistorical, culture-free, disinterested, replicable, testable, empirical substantiation of theory" (p.88) dominated social research until relatively recently (Oliver, 1992). While some argue that at the time of its development during the Enlightenment period, the positivist approach to scientific inquiry was in fact both radical (Hammersley, 1995) and potentially emancipatory (Lather, 1992), a positivist approach to social research is increasingly considered as inappropriate (as discussed on p.150-152). Key features of positivist social science can be identified[96].

Ontology and epistemology

Ontologically, positivism asserts a belief in realism, namely an external, objective reality operating according to natural laws. Its epistemology of 'objectivism' suggests that "things exist as *meaningful* entities independently of consciousness and experience, that they have truth and meaning residing in them as objects... and that... research can attain that objective truth and meaning" (Crotty, 1998:5-6)[97] with accuracy and certainty. In other words, positivism asserts that "there is a world out

---

[94] These categories are not necessarily mutually exclusive with regard to the type of knowledge which may be produced by each form of inquiry.

[95] It is acknowledged, however, that paradigms may also 'interbreed' and borrow elements from one another (Lincoln and Guba, 2000) and as such may be viewed more on a dynamic continuum of perspectives than as distinctly separate and competing conceptualisations (Martin, 1994).

[96] It is nonetheless acknowledged that a number of different forms of positivism exist (Davidson and Layder, 1994; Hammersley, 1995), and that positivism has developed over time (Crotty, 1998).

[97] Original emphasis.

there that we can...analyse independently of people's interpretations of it" (May, 1997:11). Correspondingly, the investigator must be external to and detached from the phenomenon being studied to avoid influencing it (Reason, 1998). In this way, the positivist researcher is able to obtain "innocent knowledge, untainted by political agenda" (Humphries, 1997:para. 2.1).

Methodology

Methodologically, positivism applies the interventionist principles of the natural sciences to the study of society (Davidson and Layder, 1994), controlling the phenomenon being studied either in a laboratory or statistically (Hammersley, 1995) and removing all potentially 'contaminating' context ('confounding variables') to ensure that results can be used to predict reality (Guba and Lincoln, 1989).

The 'trustworthiness criteria' used to evaluate positivist research are those of internal validity (Can the observed effect be attributed to the intervention or treatment?), external validity (Can this effect be generalised to other populations?), reliability (Could the observed effect be reproduced by someone using similar experimental methods?) and objectivity (Guba and Lincoln, 1988; Reason and Rowan, 1981b).

Critiques of positivism

Although this positivist paradigm continues to underpin much health and social care research (Bricher, 2000), it has been challenged by numerous authors in both the natural and social sciences (Lather, 1992; Oliver, 1992). One of social scientists' key criticisms has been the objective, 'value-free' status attributed to scientific knowledge by positivists. Heron (1996) argues convincingly against the possibility for such 'objective' knowledge, asserting that "there can be no objective science based on objective data: no observation can be made independent of how I choose to conceptualise them on the basis of prior theory" (p.159-160).

There are persuasive arguments to suggest that objectivity in research is not possible, as values, politics and power relations are inevitably involved in knowledge production (Denzin and Lincoln, 1998). All knowledge produced is influenced by the researcher's individual characteristics (such as gender, ethnicity and social class)

and by those of the society of which the researcher is part (Guba and Lincoln, 1989), and hence positivists actively construct scientific knowledge (Crotty, 1998). Indeed, critics of positivism argue that far from being 'neutral', positivist social research is implicitly based upon ideological social theories, and that therefore "the accounts produced are not simply false, they both reflect and serve to reproduce the status quo" (Hammersley, 1995:22) and function to "monopolize knowing in the hands of an elite few" (Reason, 1998:261).

The issue of "what constitutes 'acceptable' knowledge" (Fook, 2002:33) is of critical importance in research involving oppressed groups. The way in which positivist scientific knowledge is privileged over other forms by both research communities and governments (Humphries, 1997:para. 4.5) results, for example, in widespread emphasis upon a particular and narrow conceptualisation of distress as 'mental illness' (as discussed in Chapter One).

The way in which positivism strips human behaviour of its social context by evaluating it in 'controlled' conditions is also criticised for producing general results which are often irrelevant to local situations, thereby rendering them meaningless (Reason and Rowan, 1981a). Concern is expressed at the reductionist way in which positivist research defines people in fragmented terms of quantitative researcher-defined 'variables' or 'categories' (Reinharz, 1981; Rowan, 1981), as "a full understanding of people necessarily includes the meanings and purposes they invest in their actions" (Heron, 1996:198).

Positivism's view of research participants, as 'objects' to be studied (Park, 1992) and from whom information is to be 'extracted' (Martin, 1994), can also be seen as dehumanising and alienating (Wallcraft, 1998), reproducing oppressive social and power relations (Maguire, 1987; Sample, 1996). The 'disengaged' and 'distant' role of the positivist researcher has also been criticised by some feminist authors for disguising the complex ways in which researchers both affect and are affected by the research context and by participants, and for reinforcing the male belief that 'reason' and 'emotion' are separate concepts (May, 1997).

Positivist social research has been criticised specifically by participatory researchers for presenting an oversimplified view of social reality, reinforcing passivity, and not linking research to action to solve identified problems (Gaventa and Cornwall, 2001; Yeich and Levine, 1992). Petras and Porpora (1993) describe such research as adopting a 'hit and run' approach to the people being studied, resulting in an unequal relationship with no continuing commitment by the researcher to those communities.

Interpretative inquiry: an alternative paradigm

The interpretative paradigm is also referred to as the naturalistic or constructivist paradigm (Guba and Lincoln, 1989), and has historically been associated with theoretical perspectives such as symbolic interactionism, phenomenology and hermeneutics (Crotty, 1998). The interpretative paradigm challenges positivism's attempts to apply the laws of natural science to human beings, arguing that people act purposively, on the basis of their ideas about the world and the meaning they attach to events, and that therefore patterns observed in the social world are likely to be very different to those observed in the natural world (Davidson and Layder, 1994).

Ontology and epistemology

In contrast to positivism's external, single reality, the interpretative paradigm is based upon a relativist ontology, which states that "reality is multiple; those multiple realities are the constructions made by the human actors involved, and there are as many realities as there are actors" (Guba and Lincoln, 1988:93). Epistemologically, this paradigm challenges the notion of a subject-object separation, with a subjectivist epistemology which suggests that the interaction between subject and object *creates* the findings of the inquiry (Guba and Lincoln, 1989). This constructivist epistemology therefore suggests that meaning is constructed not discovered, only emerging when individual consciousness engages with objects (Crotty, 1998). Unlike positivism, therefore, the relationship between researcher and researched is more interactive, acknowledging the values, and social and cultural norms, of each (Guba and Lincoln, 1988).

Symbolic interactionism, developed by social psychologists, is an example of a theoretical perspective within the interpretative paradigm, which suggests that our very being derives from the processes of symbolic interactions with others (Crotty, 1998)[98].

Methodology

Methodologically, the interpretative paradigm adopts methodologies such as ethnography, grounded theory and phenomenological research (Crotty, 1998), which are concerned with understanding people's inner world, including their motives and intentions (Davidson and Layder, 1994). These methodologies therefore contrast with those of positivism, being "circular, interactive, hermeneutic, at times extrarational (intuitive, not irrational), open" (Guba and Lincoln, 1988:109-110). As a result, empirical data generated by interpretative methodologies tend to be qualitative, rather than quantitative as generated via positivist approaches (Davidson and Layder, 1994).

Furthermore, while positivism aims to produce time- and context-independent generalisations to predict behaviour, interpretative inquiry acknowledges that time and context have meaning and therefore its outcomes are presented more in the form of 'working hypotheses' which may contribute to understanding a specific situation (Guba and Lincoln, 1988).

With regard to ways of assessing research, it can be argued that criteria such as 'validity' and 'reliability', developed within positivism with its specific approach to knowledge production, cannot be applied to knowledge generated within other paradigms, and that each paradigm should evolve a set of appropriate criteria by which to evaluate its research (Guba and Lincoln, 1988). For the interpretative paradigm, criteria such as fairness, trustworthiness and authenticity have therefore been proposed (Lincoln and Guba, 2000).

---

[98] Symbolic interactionism underpins much of the work of labelling theorists such as Scheff (1966), discussed on p.18-20.

Critiques of the interpretative paradigm

Theoretical perspectives within the interpretative paradigm, such as symbolic interactionism and hermeneutics, tend to present a 'consensus' model of society whereby culture, society and power are conceptualised unproblematically, leading critics to argue that "interpretivism is overwhelmingly oriented towards an uncritical exploration of cultural meaning" (Crotty, 1998:60). Interpretative research is therefore criticised for its lack of "a critical spirit" (Crotty, 1998:58), namely "not subjecting the data and interpretative resources on which they rely to sufficient critical scrutiny, of failing to recognise that these are social products" (Hammersley, 1995:22).

Another important criticism of interpretative research is that it does not alter positivism's 'social relations of research production' (Heron, 1996), namely that researchers retain control of the definition of research questions and the ensuing process of research production (Oliver, 1992), and that as such it remains as oppressive and alienating as positivist research itself (Zarb, 1992).

The need for a reappraisal of the role and social relations of research implied by such critiques is reflected in the development of the emancipatory research paradigm.

Emancipatory research: the 'anti-positivist' paradigm

The emancipatory paradigm, also referred to as the 'anti-positivist' paradigm (Maguire, 1987) or critical inquiry paradigm (Crotty, 1998), involves "politically motivated research" (Humphries et al, 2000:3) and has a history associated with a diverse range of theoretical traditions which includes "modern social theory, Marxism, structuralism, critical hermeneutics, humanistic psychology, feminisms, Black perspectives and poststructuralism" (Humphries et al, 2000:3).

Nonetheless, some common characteristics can be identified to distinguish research approaches within this paradigm.

Ontology and epistemology

Work in this vein tends to be based upon a critical realist (Denzin, 1994) or historical/material realist ontology (Lincoln and Guba, 2000), namely that "the real world makes a material difference in terms of race, class, and gender" (Denzin and Lincoln, 1998:27) and influences the construction of people's subjective realities (Everitt et al, 1992:7).

Epistemologically, therefore, some proponents of this paradigm adopt a social constructionist perspective. Such a view can be identified in Marx's (1963) assertion that "it is not the consciousness of men that determines their social being, but, on the contrary, their social being determines their consciousness" (p. 67) (first published in 1859 as the Preface to 'A Contribution to the Critique of Political Economy'). Emancipatory research aims to support participants to "develop a critical and self-critical understanding... of the way both particular people and particular settings are shaped and re-shaped discursively, culturally, socially and historically" (Kemmis, 2001:92).

With regard to the nature of knowledge, therefore, the emancipatory paradigm challenges positivism's claims to 'objective' value-free knowledge, arguing that "all research is value-laden and is inevitably political, since it represents the interests of particular (usually powerful, usually white male) groups" (Humphries, 1997: para. 2.6). Knowledge within this paradigm is emancipatory (Habermas, 1972), and produced via critically orientated research (Henderson, 1995).

The emancipatory paradigm also challenges 'expert' and 'neutral' conceptualisations of knowledge by viewing "people's first-hand direct experience as a basis for knowledge" (Beresford and Evans, 1999:673). Indeed, it has been argued that ER approaches see knowledge production as "a liberatory act" (Henderson, 1995:59). Correspondingly, researchers working within the emancipatory paradigm tend to have an explicit, politically motivated value base with a focus upon combating inequality and oppression (Carspecken and Apple, 1992; May, 1997). 'Active knowing', i.e. knowledge for action, is also a key element of research within this paradigm (Reason and Rowan, 1981c:489).

In terms of the relationship between 'researcher' and 'researched', experiential knowing, praxis and self-reflection are key features of the emancipatory paradigm's epistemology (Reason, 1998:280). In contrast to positivism's objectivity, emancipatory research aims for "knowing based on a participative and dialogical relationship with the world" (Reason, 1988:10).

Power relations between 'researcher' and 'researched' therefore shift with regard to both the research process and knowledge production in emancipatory research (ER) (Braye, 2000). Research within this paradigm tends to be interactive, collaborative and participatory (Maguire, 1987), with researchers working together with research participants as 'co-inquirers' (Heron, 1996) on issues of interest and relevance to the community involved (Martin, 1994).

Methodology

Examples of methodological approaches within this paradigm include co-operative inquiry, participatory research[99] and participatory action research, all of which emphasise developing knowledge through dialogue for action and transformation, and sharing power with research participants (Denzin, 1994; Reason, 1998).

Important elements to include in a methodological framework for social research with emancipatory potential have been identified by Humphries et al (2000) as:

> (a) Locating the 'self' in the research process in terms of personal, social and institutional influences on research and analysis.
> (b) Exploring the political/power dimensions of empowerment.
> (c) Being explicit about the tensions that arise in research, and relating as much about how the tensions remain as about how they were resolved.
> (d) Linking research to wider questions of social inequality/social justice. (p.13)

One of the key methodological differences between the interpretative and emancipatory paradigms is that ER takes understanding, the main focus of interpretative inquiry, and acts upon it in order to bring about transformation (Ellis, 1990; Humphries, 1997; Lather, 1992). In contrast to inquiry within the interpretative paradigm (with its consensus model of society), critical research within

the emancipatory paradigm assumes social conflict and power inequalities (Crotty, 1998:63).

With regard to criteria upon which ER can be assessed, researchers within this paradigm reject attempts to apply positivist criteria such as 'validity' and 'reliability', developed from a very different approach to knowledge production. Alternative criteria are proposed to evaluate ER, such as "verisimilitude, emotionality, personal responsibility, an ethic of caring, political praxis, multivoiced texts, and dialogues with subjects" (Denzin and Lincoln, 1998:10). Reflected within these concepts is Reason and Rowan's (1981b) assertion that "validity in new paradigm research lies in the skills and sensitivities of the researcher, in how he or she uses herself as a knower, as an inquirer" (p.244) and their corresponding call for high self-awareness by the researcher to enhance this validity.

The idea of 'catalytic validity' is also proposed, defined as "the degree to which research moves those it studies to understand the world and the way it is shaped in order for them to transform it" (Kincheloe and McLaren, 2000:297). Consciousness-raising and action are therefore important quality criteria in this respect (Lincoln and Guba, 2000).

Theoretical perspectives within the emancipatory paradigm

Critical theory, Freirean pedagogy and feminist theory have all contributed significantly to the development of the emancipatory paradigm, and as such merit further consideration in the context of this doctoral work.

Critical theory

Critical theory can be identified as a key perspective within the emancipatory paradigm (Crotty, 1998), influenced by the work of a wide range of authors and philosophers including Marx (1963), Freire (1972), and Frankfurt School members such as Habermas (1972). Hammersley (1995) argues that "critical approaches generally have sought to combine two senses of the word 'critical': that implying

---

[99] Further explication of the methodology of PR, as the chosen methodological approach to this doctoral work, is undertaken later in this chapter.

reflection on the presuppositions and conditions of knowledge, and that referring to political criticisms of prevailing social forms" (p.30). Critical theory views knowledge production as political, contingent and value-laden (Rifkin et al, 2000), and highlights the way in which structural inequalities such as sexism, classism and racism mediate people's lives (Carspecken and Apple, 1992; Lather, 1992; Ulichny, 1997).

Kincheloe and McLaren (2000) emphasise the difficulty in precisely defining 'critical theory' due to its many forms, its constantly evolving nature, and the influence of postmodernism, poststructuralism and critical feminism in reconceptualising critical thinking. With these caveats in mind, they offer a useful interpretation of current-day critical theory:

> A critical social theory is concerned in particular with issues of power and justice and the ways that the economy, matters of race, class, and gender, ideologies, discourses, education, religion and other social institutions, and cultural dynamics interact to construct a social system. (p.281)

Key features of contemporary reconceptualised critical theory include those listed in Figure 8 (p.159).

An important element of critical theory is the production of knowledge in order to take action and transform structures (Crotty, 1998; Park, 2001), echoing Marx's (1974[100]) assertion that "The philosophers have only *interpreted* the world, in various ways; the point is to *change* it" (p.123)[101].

Critical theory informs the emancipatory paradigm both substantively, with regard to the topics and theories investigated (for example structure, power, culture and exploitation) (Carspecken and Apple, 1992; Lather, 1992), and methodologically, in the way research is conducted (Creswell, 1998).

---

[100] First published in German in 1888, as an appendix to Engels' 'Ludwig Feuerbach'.

Figure 8: Key features of contemporary critical theory

- Analysis of competing power interests between individuals and groups in society
- Exposure of forces that prevent individuals and groups from exercising control and autonomy in their own lives, in order to transform such forces and aim for emancipation
- Rejection of Marxist economic determinism, with acknowledgement of the existence of multiple forms of power in addition to economic factors
- Critique of instrumental or technical rationality as oppressive and more concerned with research techniques than with the purpose of research
- Consideration of the complex hegemonic, ideological and discursive ways in which power relations operate to shape people's consciousness, in addition to acknowledgement of the productive elements of power relations
- Focus upon the relationships between culture, power and domination

(Source: Kincheloe and McLaren, 2000:281-284)

Freirean pedagogy

The work of Paulo Freire and colleagues in Latin America in the 1970s has been a key influence on the development of ER approaches (de Koning and Martin, 1996a; George et al, 1996). These educators were concerned about the 'top-down' development programmes being pursued in developing countries without consultation with local people (Campbell, 2002), and left their university posts to form alternative institutions aiming to address local and regional problems via emancipatory processes (Fals Borda, 2001). This departure from an academic setting was due to "a recognition that the academic mode of production was... linked to different sets of interests and power relations from those of women and men in various social movement settings" (Hall, 2001:176). These adult educators were committed to supporting learners to establish control over their learning process and came to realise that their research practice was contradicting their education practice, leading to the development of the concept and practice of participatory research (Tandon, 1996).

---

[101] Original emphasis.

Freire ran literacy classes with poor people in Brazil to work towards 'conscientisation', namely "learning to perceive social, political, and economic contradictions, and to take action against the oppressive elements of reality" (1972:17). Freire argues that this process of conscientisation enables people to engage in the historical process as subjects i.e. those who know and act, rather than as objects, which are known and acted upon. He saw a way of achieving this via a 'pedagogy of the oppressed', which "makes oppression and its causes objects of reflection by the oppressed, and from that reflection will come their necessary engagement in the struggle for their liberation" (1972:25).

The central question then becomes how oppressed groups can participate in this pedagogy of liberation. Freire argues that oppressed groups must use perception of their situation as "the motivating force for liberating action" (1972:26). Thus Freire emphasises the importance of a dialectical relationship between action and reflection, viewing action as 'human' only when accompanied by dialogue and reflection.

Feminist theory

One of many important contributions made to debates about the nature of social research by some feminist authors was their critique of 'traditional' social research, for ignoring or distorting women's experiences, and producing alienated knowledge by insisting on the researcher's 'objective' detachment from the researched (Eichler, 1988; Maguire, 1987; May, 1997; Mies, 1993; Stanley and Wise, 1990).

Although it is acknowledged that many forms of 'feminism' and therefore of 'feminist research' exist and are contested (Olesen, 2000; Ramazanoglu with Holland, 2002), elements of feminist methodology that differ from 'traditional' social research have included the emphasis on social constructions such as gender in shaping people's consciousness and experiences, the researcher's feminist consciousness, and the researcher's own experience of being a woman (Lather, 1992; Stanley and Wise, 1983). Such feminist methodology challenges many of the binary oppositions of positivist research, particularly "objective/subjective, reason/emotion, grand theorizing/lay theorizing and researcher/researched" (Humphries, 1997:para. 2.4).

Mies (1993) provides a series of epistemological and methodological guidelines for feminist research (Figure 9), which is clearly influenced by Freire's (1972) work (as she acknowledges) and has strong resonance with the principles outlined above for the emancipatory paradigm.

Figure 9: Epistemological and methodological guidelines for emancipatory feminist research

- The idea of 'value-free' research must be replaced by 'conscious partiality', identifying with the research participants
- Feminist researchers must reverse the vertical relationship between the researcher and the researched so that the research serves the interests of women involved
- The researcher must actively participate in activities and struggles for the emancipation of women, and their research must be an integral part of this process
- The starting point for social enquiry should be a desire to change the status quo, and feminist research thereby becomes part of an emancipatory struggle focused on individual and social change
- The research process should be one of consciousness-raising both for the researcher and for the women participating in the research
- Women's individual and social histories must be studied in order to foster a collective women's consciousness
- Feminist research should facilitate women collectivising their own experiences

(Source: Mies, 1993:68)

Such feminist research approaches are clearly intended to be emancipatory in that they aim to "create knowledge which improves the position of women in society" (Humphries et al, 2000: 7) in order to address gender inequality (Everitt et al, 1992). Despite feminist critiques of Freirean approaches for ignoring gender and using universal categories (Maguire, 1987), similarities between feminist and Freirean, participatory approaches do include their "visions of transformation; they share common assumptions concerning oppression, consciousness and historical change" (Humphries et al, 2000: 9), and their conceptualisations of research participants as active subjects rather than objects (Everitt et al, 1992:15).

Critiques of emancipatory research

Criticisms of ER approaches include their over-reliance on 'top-down' theory, their emphasis on praxis and ideology at the expense of clear and systematic explication of research practice (Reason, 1998), and "their tendency to impose their voices and values on the groups studied" (Denzin, 1994: 509). The lack of acknowledgement of "the ways in which all groups may be destructive and distort their experience" is highlighted as potentially problematic by Reason (1998). Truman (2000) cautions against conflating the benefits from taking part in ER with empowerment, arguing that "researchers need to ask questions about what sort of empowerment is possible through social research" (p.32).

It is also important at this stage to note different interpretations of emancipatory research emerging in social science literature. The view of ER as a paradigm highlighted above has a relatively long tradition in social research (see p.154), within which PR is identified as an emancipatory methodology (Henderson, 1995; Maguire, 1996).

However, ER has also been identified as a particular methodology within more recent disability literature, underpinned by the social model of disability and which fully reverses the social and material relations of research production such that disabled people control every aspect of the process, funding and dissemination of research (Goodley, 1997; Oliver, 1992, 1996; Stone and Priestley, 1996; Ward and Flynn, 1994; Zarb, 1992).

From this viewpoint, many forms of critical inquiry within the social science emancipatory paradigm, including PR, would be considered unable to achieve emancipatory goals as they do not address the unequal material relations of research production i.e. resources may rest with researchers rather than with research participants (Ellis, 2000; Evans and Fisher, 1999).

I return to the debate about whether PR can be emancipatory in the sense proposed by the disability movement on p.176. However, more general social research literature does locate PR within this paradigm, and for clarity of conceptual thinking

I retain this use of the term emancipatory research, i.e. as a social research paradigm, rather than as a methodology developed by disabled people (and not well linked to this broader literature). This debate highlights the importance of distinguishing between paradigms and methodologies adopted (Harrison et al, 2001).

Although there is acknowledgement within mental health literature of the need to involve service users in research in more participative ways (e.g. Beresford, 1997; Rogers et al, 1993), there was little published literature on ER methodologies as they might relate to mental health service users at the time of searching to identify an appropriate research methodology for this doctoral work (exceptions being Beresford and Wallcraft, 1997, and Nelson et al, 1998). The following section therefore presents my rationale for choosing an emancipatory research approach and participatory research methodology for these doctoral studies with mental health service users.

Rationale for choice of research approach

This chapter has outlined the ontological, epistemological and theoretical considerations involved in choosing an appropriate research methodology for this study. However, this choice was also influenced by my own biography and values, which framed the way in which I approached this research.

Researcher's biography and value position

May (1997) suggests that researchers' values enter into the research process at several points, including personal interests leading to the research, the aims, objectives and design of the research, data collection and analysis processes, and the use made of research findings. Kincheloe and McLaren (2000) suggest that "critical researchers enter into an investigation with their assumptions on the table, so no one is confused concerning the epistemological and political baggage they bring with them to the research site" (p.292).

My motivations in choosing to undertake doctoral studies in the field of mental health were largely personal, resulting from experiences of varying degrees of mental

distress amongst my family and friends over several years. These experiences gave me a strong sense of injustice in relation to the mental health system's treatment of people in distress, which was compounded by subsequent research experience. I was privileged to be able to learn directly from service users about their experiences of oppression and disempowerment within the mental health system via various research projects undertaken for my paid work.

These learning experiences contributed to and reinforced my belief that people with experience of mental distress are systematically disadvantaged and disempowered by society, and that this disadvantage is reinforced by cultural stereotypes and by individual interactions. My value position is that this oppression of mental health service users is unacceptable, as people with experience of mental distress should be able to assert their rights as citizens and lead the lives that they choose. In opposition to the commonly perpetuated view of mental health service users as irrational and incompetent, my experiences and learning have shown me that people with experience of distress are autonomous, self-directing individuals with the right to make their own decisions about their lives and to contribute to society.

I recognise that research involves complex power relations, and that as a white middle-class well-educated woman working in an academic setting (although relatively powerless within that hierarchical setting) I occupy a position of privilege in relation to certain oppressed groups in society. An important element of research within the emancipatory paradigm is being aware of the tensions and power relations that such characteristics create, and being explicit about how these may have influenced the research process.

It is clear from the arguments reviewed above that research processes and outcomes can contribute to maintaining systems of oppression, or can be used as tools for social action and change (Reason and Rowan, 1981c:489). I am committed to supporting research which aims to facilitate action and positive benefits for people, particularly when research involves oppressed groups (Kincheloe and McLaren, 2000). These beliefs affected the way in which I undertook this doctoral research, including my conceptualisation of the research methodology.

Defining my research question and methodology

As highlighted on page 1 of this dissertation, my original proposal for this doctoral research was to examine the effectiveness of advocacy and its potential use as a method of 'empowerment' for mental health service users. However, as I began to explore the literature, I realised that attempting to define and measure outcomes was a complex and contested process, not least in relation to whose definition should take priority (Nocon and Qureshi, 1996).

My exploration of appropriate research methodologies via literature reviewing, formal research training, and other students' experiences, both fuelled my interest in critiques of positivism and the concept of 'value-free' knowledge and suggested a more interactive and emancipatory approach to research. I became interested in participatory research's emphasis on methodology as a means of countering oppression and power imbalances, in line with the literature on emancipatory research. PR also struck chords with my belief that people with experience of mental distress should be central in the research process, and should obtain practical benefits from research.

At the time of choosing a research methodology for this work (i.e. 1997), there was some description of PR in the disability literature but very little in mental health literature. I was therefore keen to see whether PR could be a valuable approach to research with people with experience of mental distress, given the commonalities of experience of oppression and discrimination (as highlighted on p.34).

A shift in emphasis in my research question therefore occurred relatively early on in my doctoral studies. From wanting to look at advocacy as a method for people to be heard, I came to feel via exploration of more participative research methodologies that it was not appropriate for me to state in advance issues of importance for people using mental health services, and that these issues should instead be defined by mental health service users themselves. This led me to refocus my research to consider the potential of PR as an empowering process by which people might be able to put forward their views and achieve change. The research question that the group chose to address could then be any issue of importance to them, as the

particular topic(s) would be secondary in interest for me to the processes occurring during PR.

Participatory research methodology

Participatory approaches

Various research approaches with a participatory component have been identified, including action research (Hart and Bond, 1995), participatory action research (PAR) (Whyte, 1991), participatory community auditing (Packham, 2000), empowerment evaluation (Fetterman, 2000), participatory evaluation (Bradley et al, 2002), partnership research (Lloyd et al, 1996), collaborative inquiry (Humphries et al, 2000), inclusive research (Walmsley, 2001) and agricultural development techniques such as Rapid Rural Appraisal (RRA) and Participatory Rural Appraisal (PRA) (Campbell, 2002).

There are rather blurred distinctions between these participatory approaches, which differ according to authors[102]. It has been suggested that it is important not to adopt "a purist attitude towards participatory research" (de Koning and Martin, 1996a: 3) in attempting to define different methodologies. The key differences between approaches, such as they are, seem to lie in the extent of participation involved, and their consideration of power issues. For example, it has been suggested that action research does not address unequal power relations and oppressive social structures in the same way that PR does (Nash, 1993; Nelson et al, 1998; Sayer, 1992). However, some authors have begun to use 'action research' as an umbrella term to include all participative and collaborative forms of inquiry, including PR (Bell, 2001; Reason and Bradbury, 2001a). 'Action research' will not be used in this way in this dissertation, as I believe that this does not aid clarity of conceptualisation, but literature which uses the term thus will be drawn upon where relevant.

[102] For example, many authors talk about PR and PAR interchangeably (e.g. de Koning and Martin, 1996a), or refer to P(A)R (e.g. Fals Borda, 2001). PAR was originally used more in the development field, but increasingly literature about PAR appears to refer to the same research as PR. For the purposes of this chapter, the term PR is used, but literature on PAR is drawn upon when it is clear that authors are using the terms interchangeably.

Exploring the nature of participatory research

A range of knowledge bases to PR methodology has been identified, with different theoretical influences (Humphries et al, 2000). These include humanistic psychology (Reason and Rowan, 1981c), Freirean thought (Freire, 1972), critical theory (Habermas, 1972) and feminist approaches (McDonald, 2001; Shaw, 2000) (as discussed on p.157-161). Humphries et al (2000) suggest that while participatory approaches informed primarily by humanistic psychology emphasise experiential knowledge and have a relatively individualistic focus on people as self-directing actors engaging in collaborative inquiry (e.g. Heron, 1996; Reason and Rowan, 1981c), the Freirean approach expands these ideas to consider the political, economic and social context, incorporating Marxist views about oppression and emphasising education and social action.

Early work on developing PR by Freirean adult educators identified key concepts, including: research being of direct benefit to the community; involving the community in all stages of the research process; emphasising ongoing dialogue within the research process; and aiming for liberation, action and the solution of problems via research (Hall, 1978:161-163). Many of these concepts can be seen to echo those outlined in the above discussion of the emancipatory paradigm (p.155-157).

As knowledge is viewed by participatory researchers as a crucial basis of power and control (Reason, 1998), it is argued that the "democratization of knowledge creation" (Stoecker and Bonacich, 1992:6), control and application should be central to attempts to support oppressed people in their emancipation (de Koning and Martin, 1996a; Maguire, 1987). This knowledge creation is achieved through a partnership between researchers and oppressed people (Hall, 2001), where power is shared (Nelson et al, 1998; Park, 1993) throughout the research process (Bricher, 2000; Henderson, 1995; Kemshall and Littlechild, 2000). In this way, PR "challenges the status and power that is exercised by professional researchers and emphasises the demystification of the research process" (Dockery, 2000: 95).

A key belief of PR is that people have the capacity to critically reflect on their social reality and find solutions to their own problems (Cocks and Cockram, 1995). PR recognises peoples' views as legitimate knowledge (Park, 1992; Stoecker and Bonacich, 1992), thereby challenging the 'top-down' approach to knowledge production (Green et al, 1996) as "members of oppressed groups become actors in a creative process rather than targets of intervention" (Finn, 1994:26). The dynamic development of knowledge through dialogue in PR leads to the production of "not just factual knowledge but also interpersonal and critical knowledge, which defines humans as autonomous social beings" (Park, 1993:12) and uses understanding gained from knowledge creation to take action. Mutual consciousness-raising is an important method used in PR to develop knowledge in this way (Henderson, 1995).

PR therefore entails a three-part developmental process of investigation, education and action for social change (Maguire, 1987; Reason, 1988). The action element of PR is of critical importance, aiming to bring about material changes in people's lives (Park, 2001).

PR may be initiated by a group or community, or by a researcher wishing to work with a group or community to address social problems (Dullea and Mullender, 1999). Although 'outside' researchers are not required in PR (Hall, 2001), where they are involved they act as a resource to the group (Fine et al, 2001), and demonstrate commitment to them rather than detachment (David, 2002; Reason, 1998), as is advocated in traditional research making claims to 'objective' knowledge production (Lerum, 2001).

A core belief in PR is that research is political (Swantz and Vainio-Mattila, 1988), for example in its distribution of power. Researchers therefore adopt an explicit value position in relation to countering oppression (Cocks and Cockram, 1995; Stoecker and Bonacich, 1992), acknowledging that "a participatory worldview is a political statement as well as a theory of knowledge" (Reason and Bradbury, 2001b: 9).

With regard to appropriate research methods to be used in PR, it has been suggested that the key feature of PR is not the methods adopted, which are often similar to those used in 'traditional' research, but the "methodological contexts of their application" (Cornwall and Jewkes, 1995:1667). Both qualitative and quantitative methods are used, depending on the needs of the group (Green et al, 1996; Martin, 1996)[103].

A key aspect of PR, and one which distinguishes it from some other participative approaches to research, is the equal relationship between researcher and participants, or 'co-researchers'. Consideration of levels of participation in research highlights this difference.

Participation in research

PR requires more than just participation in research. Indeed, it has been argued that "participatory research... is a process that is biased in favour of the least powerful. It is not a neutral process of stakeholder consultations" (Hall, 2001:175). The continuum of user involvement (Philpot, 1994) and the ladder of participation (Arnstein, 1969) highlighted in Chapter Three can also be applied to user involvement and participation in research (Fawcett and Hearn, 2001; Watt et al, 2000), which ranges from non-participation to full user control (Kemshall and Littlechild, 2000; Lindow, 2001). There is likely to be "a relationship between the extent of service users' involvement in research and its capacity to serve an empowering function" (Beresford and Evans, 1999:674). A continuum of participation in research can therefore be identified, as highlighted in Figure 10 (p.170).

The ethos and underpinning values of PR are more in line with the democratic model of involvement (see p.97-98) than with the consumerist model. It would therefore be expected that PR activities would be located towards the maximum end of a continuum of involvement or participation in research. Cornwall and Jewkes (1995) suggest that PR should be located at the collegiate level, although others argue that

[103] The methods used in the PR project undertaken as part of these doctoral studies are outlined in Chapter Six.

the collaborative level of participation could also be defined as PR (Petras and Porpora, 1993).

Figure 10: Cornwall and Jewkes' continuum of participation in research

CONTRACTUAL
Researchers contract people into their projects to take part.
|
|
CONSULTATIVE
Researchers ask people for their views before they make interventions.
|
|
COLLABORATIVE
Researchers design and manage projects, but work together with local people on their implementation.
|
▼
COLLEGIATE
Researchers and local people work together as colleagues with different skills to offer, in a process of mutual learning where local people have control over the process.

(Source: Cornwall and Jewkes, 1995:1669)

A stage beyond the collegiate level of participation would be service users defining a research question and implementing research without input from a 'professional' researcher (as advocated by the disability movement via ER, and other service users via 'user-controlled research') (Beresford, 2002b). This possibility is not fully addressed by PR authors, even though it is a logical progression. A similar option, also not covered explicitly by the literature, would be a researcher 'skilling up' participants who then conduct research themselves with the researcher merely available to call upon. However, such a model would clearly be difficult to adopt in the context of doctoral research studies.

In reality, there are likely to be varying levels of participation in and control of the PR process by participants at different stages (Kemshall and Littlechild, 2000), depending on their wishes and circumstances.

PR, power and empowerment

Adams (1998) emphasises the potential for empowerment via PR:

> Participatory methodologies offer the most conceptually sound, rigorous and practical ways of facilitating empowering approaches to theorising, practice and research in social work. Such approaches would be more likely than at present to accommodate challenges to existing systems and services by those on their receiving ends, or excluded from them. (p.159)

Power and empowerment are indeed central issues in PR discourse (Martin, 1996; Nelson et al, 1998). Rifkin et al (2000) state that PR "focuses on the involvement of marginalised people who have traditionally been objects not subjects of research and sees as a major objective to empower them through this process" (p.50). It has been argued that "participation should genuinely be empowering and not just a situation where local people work with a researcher for the latter's convenience" (de Koning and Martin, 1996a:3). Not all participatory researchers are explicit about how they view empowerment, but some do comment on the nature of power and empowerment involved in PR (e.g. Yeich and Levine, 1992).

The early PR work undertaken using a Freirean approach viewed power and oppression as binary concepts, with the 'oppressed' and 'oppressors' as clearly identifiable groups of powerless and powerful people respectively (Humphries et al, 2000). This approach has been criticised for being oversimplistic (Gaventa and Cornwall, 2001) (as discussed on p.37-38).

Lukes' three-dimensional view of power (outlined on p.50-51) suggests that "the control of knowledge as a way of influencing consciousness is critical to the exercise of power" (Gaventa and Cornwall, 2001:71). Hence, PR can be empowering if it manages to "create more democratic forms of knowledge, through action and mobilization of relatively powerless groups on their own affairs, in a way that also involves their own critical reflection and learning" (Gaventa and Cornwall, 2001:76).

Nonetheless, Lukes' work has been criticised for viewing power solely as a repressive resource, and for not identifying positive aspects of power. Foucault (1980) identifies power as a productive force, present in all relations and operating

through discourses and practices. Foucault's work suggests that people can increase their power, for example their power to act, without limiting other people's opportunities as a constant-sum conceptualisation of power would suggest (Gaventa and Cornwall, 2001). However, the emphasis on local and specific power relations rather than structural inequalities is problematic for PR in that it fails to recognise broader sources of oppression in society (see p.59) and therefore "questions any notion of 'emancipatory' research, which depends on an acceptance of the transcendent goal of liberation as a starting point for research" (Humphries et al, 2000: 12).

The need to combine the Foucauldian perspective on power relations with some acknowledgement of the structural nature of power was advocated in Chapter Two (p.60), and this argument can also be applied to the conceptualisation of power within PR. It has been argued that for research to be empowering, it needs not only to give a voice to oppressed people but also to locate these voices within the wider social context (Truman, 2000). This view supports PR's focus on understanding and challenging the social and structural context of oppression as a means of empowerment, in addition to its emphasis on 'democratising' knowledge production (congruent with Foucault's views on knowledge, power and discursive formations, discussed on p.54-55).

Literature identifies common elements of empowerment as personal development, participation, consciousness-raising and social action (see p.86), which can be seen to correspond to PR's elements of knowledge, consciousness and action. Yeich and Levine (1992) argue that PR's components of research, education and social action promote empowerment in a range of ways. Research is identified as contributing to individual empowerment by developing people's skills and knowledge to understand themselves, and collective empowerment by providing a basis for action towards social change. Education contributes to empowerment by developing common knowledge and critical awareness, which can build confidence and help people to understand oppressive forces in their lives. Additionally, social action can contribute to individual empowerment due to the knowledge and skills gained via activism, and

collective empowerment via structural change. All three components of PR are identified as promoting collective empowerment via group cohesion[104].

Other authors echo this view by highlighting potentially empowering activities and processes involved in PR at both individual and collective levels. These include: information sharing and consciousness-raising (Barnes, 1999b; Tetley and Hanson, 2000); production of alternative, local forms of knowledge (Reason and Bradbury, 2001b; Sohng, 1998); the corresponding challenging of professional 'expertise' (Dockery, 2000); increasing access to resources to have greater control over decision-making (Martin, 2000); and creating 'space' for people to take action to improve their situation (Swantz and Vainio-Mattila, 1988).

It has been suggested that while PR might not be able to achieve empowerment at a structural level in terms of changing oppressive social systems, it can contribute towards effecting such change via knowledge production, consciousness-raising and action to challenge professional and institutional power (Sohng, 1998).

Despite the many strengths of PR identified in the literature, tensions and potentially problematic issues have also been highlighted, which merit exploration.

Issues in PR

'Validity' and 'reliability' of PR findings

The 'validity' and 'reliability' of PR findings is a debated issue (Kemshall and Littlechild, 2000), and one for which PR has been criticised (Bradley et al, 2002). However, it is argued here that as PR is based upon an emancipatory rather than positivist paradigm, the knowledge produced by PR is different to that produced by natural sciences from which the concepts of validity and reliability are borrowed (Bradley et al, 2002; Park, 2001). Using Habermas' (1972) conceptualisation of knowledge-constitutive interests, knowledge generated via PR is interactive and critical rather than technical, and therefore "validates itself in creating a vehicle of

---

[104] In the next chapter, on research design, the definition of empowerment adopted in this dissertation will be operationalised with regard to its potential relationship to the PR work undertaken.

transformation and in overcoming obstacles to emancipation - both internally and with respect to the external world" (Park, 1993:16).

PR suggests that knowledge cannot be unaffected by the conditions in which it is produced, as positivist research claims, and therefore aims to produce "situated knowledges" (Dockery, 2000:98) generated in specific circumstances. Finn (1994) refers to Lather's two key questions on validity in feminist research in this respect, namely "How effective is the project's assessment and representation of the experiences of the participants, and the project's 'catalytic validity' or capacity to mobilize action?" (p.35). PR is a 'valid' method in this respect, "in that the participation of the community in the research process facilitates a more accurate and authentic analysis of social reality" (Nash, 1993:40) and a more genuine representation of people's experiences (Dockery, 2000).

With regard to reliability, Finn (1994) suggests that this must be balanced against the relevance of knowledge acquired for facilitating community empowerment. There is therefore a distinction between the analytical discourse of debates about 'reliability' and the political discourse of 'relevance' which is propounded by participatory researchers.

The aims of PR also differ from those of positivist social research:

> ...outcomes should include action on attitudes and structures that inhibit self-worth, social justice or liberation. So here the criteria of successful research relate more to empowerment or social justice than to increased efficiency or generalizable knowledge. (Kinsey, 1987:viii)

Hence it can be argued that the positivist scientific concepts of 'validity' and 'reliability' cannot be applied to emancipatory research such as PR, which is more concerned with relevance to the communities involved and with research's contribution to action and empowerment.

What differentiates PR from a professional practice approach?

It has been argued that PR is similar to community development practice (Dullea and Mullender, 1999), in that it aims to build communities' capacities to improve their situation and take action to challenge unequal social structures. Similarities have

also been identified between PR and empowering social work practice models[105], both in relation to their underpinning values and to the techniques used. Both PR and empowering social work practice approaches emphasise structural analysis of people's situation (rather than viewing them as 'victims'), empowerment, positive change in people's lives, the power of collective action, and people's rights to control their own lives (Everitt et al, 1992; Mullender and Ward, 1991). Furthermore, PR and social work both often use groupwork as a technique to facilitate such processes (Brown, 1997), for example via dialogue and critical consciousness-raising (Lee, 2001).

These similarities are unsurprising given the common origins of both the research and practice approaches, for example the work of Freire, of feminists, and of other civil rights movements (Adams, 2003). However, there nonetheless exists a difference between PR and such practice approaches in that PR's primary focus is knowledge generation leading to action, whereas social work's main concern tends to be maximising people's self-determination and control over their lives (Lupton and Nixon, 1999; Payne, 1997) via processes of personal growth and development (Brown, 1997). In relation to groupwork, for example, groups are clearly used in many contexts for different purposes. It is therefore likely that similarities exist between PR and social work practice approaches, as the group processes and dynamics may be similar. However, purposes of groupwork in social work are diverse depending on the context (Brown, 1997), whereas in PR the purpose of groupwork is to undertake research based on areas of common concern and to collectively act upon its results. While Mullender and Ward's (1991) self-directed groupwork model, for example, involves some similar stages to those of PR (such as exploring problems and taking action), it does not entail an explicit research phase.

It is viewed in this dissertation as positive that research and practice models exist which advocate working in similar ways, with shared value bases, with oppressed groups. As argued by Everitt et al (1992:47-48), research and practice should be seen as interdependent, contributing to developing the methodology of the other.

---

[105] Examples of such models include Mullender and Ward's (1991) self-directed groupwork and Lee's (2001) empowerment approach to social work practice.

Can PR be emancipatory?

Disability writers have criticised PR for merely "improving the existing social and material relations of research production, not challenging and ultimately eradicating them" (Oliver, 1997:26) and have therefore argued that PR cannot be defined as emancipatory research (Finkelstein, 1999). Although similar characteristics can be detected, these disability writers do not refer to the social science tradition of emancipatory research (described on p.154-163), which locates PR within this paradigm, and instead suggest a very specific definition of ER (Walmsley, 2001).

This latter definition argues that ER must be based specifically upon the social model of disability (Oliver, 1992; Zarb, 1992) and must therefore research disabling social and material barriers to contribute to people's emancipation (Finkelstein, 1999; Stone and Priestley, 1996). It argues that disabled people should be in full control of research, including funding, for this research to be viewed as emancipatory (Ramcharan and Grant, 1994).

It has been suggested that PR is concerned with empowerment, while ER is concerned with emancipation i.e. the "liberation from restrictions which is brought about by social change" (French and Swain, 1997:28). It is nonetheless acknowledged that individual empowerment and collective emancipation are mutually related, with each contributing to the development of the other.

I would argue that participation in ER as defined by the disability movement would not be accessible to all people in oppressed groups, as it appears to be feasible primarily for people already politicised and involved in groups with infrastructure to support research activities. I would therefore suggest that PR could be a positive step towards carrying out this form of ER, particularly for people unaccustomed to being involved in such work (as was the case for our group), as support and research infrastructure is available from the 'external' researcher. This point is echoed by Lloyd et al (1996) when they question disability activists' assertion that empowerment can only occur via an emancipatory methodology whereby disabled people undertake research on their own:

> Empowerment and partnership will not just happen; they must be resourced... perhaps by providing opportunities for (people) to acquire knowledge, understanding and support which will increase their self-confidence, power, control and choice. (p.306)

Nonetheless, disability writers' contributions are valid in forcing participatory researchers to acknowledge that they do exercise some control over the research process, often having responsibility for funding and taking control of dissemination of findings (Kemshall and Littlechild, 2000). It has been suggested that PR is more concerned with promoting participation and ER is focused upon control, i.e. is further up the 'ladder' of participation (p.101) (Northway, 2000a; Walmsley, 2001). PR might therefore only be able to contribute towards the emancipatory goals it espouses, but the disability literature should be more explicit in acknowledging that PR does nonetheless state such goals in line with its emancipatory origins. A clear example of a limited interpretation of PR's aims is given by Evans and Fisher (1999) when they state of disability research that:

> This new research is intended to follow the emancipatory, rather than the participatory, model: that is, it is designed primarily to enhance the power of service users... (p.103)

The PR literature described above clearly emphasises its aim of enhancing oppressed people's power and of addressing unequal power relations between co-researchers. Several other examples of disability writers making claims for differences between ER and PR are in this vein, in that they do not appear to have fully reviewed the well-established PR literature (Northway, 2000a).

Can PR meet its aims?

PR's aim of effecting social change and transformation could be seen as ambitious, in that "most participatory researchers recognize that the social and political changes generated by participatory research projects often end with the participants as well" (Henderson, 1995:62), highlighting the distinction between countering oppression within the research process itself and research's capacity to counter wider oppression in society (Northway, 1998).

There is also a relatively unsubstantiated assumption in PR literature that the process of empowering groupwork will ultimately lead to collective action to transform

social structures (Baistow, 1994). This highlights the need for participatory researchers to be explicit about whether and in what way processes of groupwork and collective social action link together.

There are likely to be limits on the extent to which PR can be a fully empowering process if it is funded by groups or institutions whose agendas differ from those of the participants (Williams and May, 2002). The "structural and contextual constraints upon change" (Kemshall and Littlechild, 2000:235) mean that although PR might be able to achieve specific local changes, culture change in communities or organisations is more difficult to effect.

These constraints also highlight the importance of considering how long-term participation can be sustained to increase possibilities for social action and change (Warren and Maltby, 2000). It has been argued that PR should 'give back' to the community involved, and that therefore "creating a legacy of inquiry, a process of change and material resources to enable transform(ation) are crucial to the PAR project" (Fine et al, 2001: no page number). PR should ideally form part of an ongoing process of social action and change in communities (de Koning and Martin, 1996a).

Feminist critique of PR

Despite PR's emphasis on oppression and emancipation, early PR literature was criticised for 'hiding' women's voices and making gender indistinguishable by the use of terms such as 'the oppressed' and 'the community' (Humphries et al, 2000; Maguire, 1987, 1996). It has been suggested that this androcentrism mirrors the male bias of the movements which influenced PR's emergence, such as the adult education movement (Maguire, 1987). Hence, while PR has challenged class bias, it has often failed to challenge the gender bias of much social research. The need to give explicit attention to gender throughout the PR process, and to link the theoretical traditions of feminist scholarship and PR more systematically (Maguire, 2001), have been emphasised.

There is little mention in PR literature of issues of ethnicity (Bell, 2001). Maguire, for example, does not extend her analysis of published PR projects to consider the extent to which they are sensitive to ethnic differences within communities. It is therefore also important for participatory researchers to give attention to ethnicity issues.

Conclusions

Participatory research and the emancipatory research paradigm

It has been proposed in this chapter that a social researcher's choice of paradigm will depend on their values, views on human behaviour, definitions of knowledge and its role in society, and views on the purpose and remit of research[106].

Both positivist and interpretative research approaches have been shown to entail oppressive social and material relations of research production, and to present a relatively uncritical view of knowledge production. It is therefore argued in this chapter that an emancipatory approach is most likely to generate the critical knowledge needed to both alter the social and material relations of research production and to tackle broader social inequalities, and its increased use in social science research is thus advocated.

It is argued in this dissertation that mental health service users as a group experience oppression, disempowerment and discrimination in society, and hence it is vitally important that research should at the very least not add to this oppression by treating people as passive objects with no power during the research process. With this value statement in mind, the emancipatory research paradigm is proposed as an appropriate approach to working with mental health service users in an anti-oppressive and empowering way (see p.154-161). PR, as a social research methodology underpinned by the emancipatory paradigm, therefore holds potential for working with people with experience of mental distress. PR locates consideration of power, a key issue in the lives of mental health service users, at the centre of the research

[106] It should be noted, however, that such 'choice' may in reality also be constrained by practical issues such as research training, academic discipline, funding arrangements and academic institutions.

process. The joint PR process of investigation, education and action gives co-researchers the opportunity to learn more about their situations and experiences, define problems, and take action to gain practical benefits from research.

PR and theories of power, empowerment, involvement and participation

By drawing links between PR theory and the theories and models of power, empowerment, involvement and participation outlined in Chapters Two and Three, it is clear that PR work can be consistent with an approach to power which combines structural analysis with a Foucauldian recognition of local power relations, knowledge production and discourses. PR aims in theory at least for empowerment at the individual, group and structural levels, although the extent to which the latter is achievable and might result in social change can be questioned. Nonetheless, PR theory does resonate with the democratic models of involvement and participation proposed in Chapter Three, and aims to work towards maximising involvement and participation of oppressed groups. As such, and despite its limitations discussed in this chapter, PR is advocated as an appropriate methodological approach to exploring the key issues under consideration in this dissertation, namely oppression, power and empowerment.

The next chapter links PR methodology to the research design developed for this doctoral work and provides detailed exposition of the nature of this research design.

Chapter Six: Research Design and Methods

Introduction

Denzin and Lincoln (1998) describe a research design as "a flexible set of guidelines that connects theoretical paradigms to strategies of inquiry and methods for collecting empirical material" (p.28). This chapter presents the research design for this doctoral work. Strategies of inquiry used are linked to the methodological and theoretical frameworks outlined in Chapter Five, and decisions made about the research site and about which research methods to use to achieve the research aims are then explained. Ethical considerations underpinning decisions about research design and implementation are also highlighted, and the framework developed for data analysis is described.

Links between research methodology and design

The research methodology adopted for this doctoral research was participatory research. As detailed above, exploration of appropriate methodologies for working with mental health service users as an oppressed group led to a belief that the PR methodology would not further oppress and disempower the people involved. The values and principles described in the previous chapter which characterise PR, as a methodology within the emancipatory social research paradigm, were explicitly incorporated into the design and implementation of this research.

PR methodology emphasises the creation of knowledge via dialogue and participation, rather than via the 'traditional' approach of a researcher 'extracting' data from 'subjects'. This emphasis upon dialogue clearly implies people sharing and reflecting upon experiences together, which translated into the need to establish a group to meet regularly over a period of time to undertake PR. The key activities involved in PR, namely investigation, education and action, are also likely to be achieved most effectively as joint activities. It is acknowledged, however, that people's participation in groups will vary, and it is therefore important to enable all group members to participate in decision-making from the start of the process (Reason, 1998:264-265).

PR methodology emphasises the importance of addressing traditional power imbalances between 'the researcher' and 'the researched', by reversing the social relations of research production so that participants have control of the research process. I worked to incorporate these principles into the research design by explicitly promoting an ethos of shared decision-making amongst participants (or 'co-researchers'), and by attempting to place all decisions to be made about the content and process of the PR group's activities with co-researchers. These endeavours were not always successful, and variations occurred throughout the project in the degree to which co-researchers wanted to take on decision-making and roles of responsibility[107], but I nonetheless attempted to apply the principle of co-researcher control throughout. Research issues to be addressed were identified by co-researchers as being of interest and relevance to their lives, as a result of their sharing of experiences, rather than being predefined by myself. Furthermore, action taken on the basis of the group's research findings was intended to directly serve co-researchers' interests[108]. Flexibility in timing is also important (Finn, 1994), as it acknowledges that people want and need to work to their own agenda and timescale rather than that of external researchers, and I tried to ensure that such flexibility was possible (within the constraints of conducting research for doctoral study).

PR methodology also implies the promotion of participation at each stage of the research process, and I consciously attempted to facilitate such participation during each phase of the project. Co-researchers' participation was fuller during some phases (for example undertaking group interviews and taking action on the findings) than others (for example data analysis), for various reasons which are explored in subsequent chapters, but was nonetheless a key principle underpinning the research design.

PR's methodology explicitly acknowledges the oppression that certain groups experience in society, and commits to countering this oppression. Implied within such a commitment is a view of all oppressed people as valued, self-determining agents able to identify and solve their own problems, thus reversing the traditional

---

[107] These variations will be discussed as findings are presented in subsequent chapters.
[108] I acknowledge, however, that the research was also serving my interests indirectly in the sense of providing data upon which to base this dissertation and accompanying academic publications.

paternalistic approach of some 'helping' professions. I incorporated such a commitment into my research design by seeking to conduct a collaborative and participative research project with people who had experienced considerable oppression, namely those with long-term experience of mental distress and subsequent contact with mental health services, and by committing to work with people in a way which emphasised the valuable contributions they could make and reinforced their strengths and skills.

PR methodology suggests a very different role for the researcher than that advocated by more traditional, experimental research methodologies, which also has implications for research design. Rifkin et al (2000:103) suggest that it is important "continually to examine the researcher's... attitudes and behaviours in the community". Throughout our PR project, I attempted to work in a non-directive, facilitative way with co-researchers (Bradley et al, 2002; Park, 1993), placing decisions with them and offering my research knowledge and skills to them as enabling resources and tools rather than as any form of 'expertise' (Dockery, 2000; Packham, 2000). Unlike traditional research approaches which expect the researcher to remain 'neutral' and 'detached', I was explicit with co-researchers about my values, beliefs and personal motivations for working with them from the start of the project, and engaged with issues discussed on a personal level. I also committed to 'taking their side' throughout the process, for example when taking action to achieve desired changes, explicitly taking the role of activist rather than that of 'detached observer'.

Multiple skills and characteristics are required by a participatory researcher, including empathic understanding, listening skills, sensitivity, responsiveness and adaptability (Ellis, 1990; Richardson, 1997). I felt I had developed such skills both via my work experience as a volunteer trainer and help line worker for an HIV organisation, and my prior experience of undertaking qualitative research with disadvantaged groups (including mental health service users). PR also implies that ethical considerations should go beyond those of obtaining consent and not causing harm to fostering positive benefits and nurturing human relations, which I incorporated into my way of working with co-researchers.

In addition to PR methodology and its influence on research design, a key aim of this dissertation is to explore the nature of empowerment and the potential of PR as a strategy for empowerment. Work on empowering practice has highlighted the importance of collaboration and mutual respect, a focus upon strengths, shared decision-making and active participation, the provision of enabling experiences and learning opportunities, and commitment to act upon research findings to achieve positive change (Fitzsimons and Fuller, 2002). Similarly, empowering evaluation has been identified by Adams (2003) as involving service users as co-producers of research, collaborating throughout the research process. Although these texts were not available at the time of designing this research project (1997), elements of these empowering models can clearly be identified in the PR methodology and corresponding research design highlighted above, confirming that the way in which this doctoral project was designed did have empowering potential for participants.

All of these methodological issues were important in conceptualising and implementing the design of this PR project. The research design was also necessarily informed by existing PR models. While the theoretical literature on PR is relatively extensive and there are case study examples of PR (e.g. de Koning and Martin, 1996b), there were fewer instances of models of PR available in the literature at the time of identifying one to use for this doctoral work[109]. Maguire (1987)'s framework for conducting PR was one of the few clear models available at the time of designing this research. Her framework incorporated many of the methodological and design elements highlighted above and therefore provided a useful starting point for developing my research design. She identifies five phases of a PR project, which are summarised in Figure 11 (p.185).

Despite conducting PR as a time-limited project with a group of women, Maguire (1987) does not provide an account of how she negotiated ending the project. Northway (1998) highlights the lack of discussion of ending or withdrawing from research within PR literature. She suggests that this neglect may be due to the view

[109] This lack of models of PR may partly be due to the assertion that there is no one method or design for PR (Hall, 2001; Tetley and Hanson, 2000) and that the model used "must evolve out of and in response to the unique conditions and context of the specific situation" (Maguire, 1987:40).

of PR as a continuous process where one project leads into another, and to PR's emphasis on personal and social transformation as an ongoing process.

However, where specific projects are being conducted, it is important for researchers to give explicit consideration to their end as part of the PR process. Such consideration is particularly important where vulnerable groups are involved, as they may have limited social networks and therefore experience endings negatively (Northway, 2000a). Often with PR carried out for doctoral studies, a group is initiated by someone external to that community and formed for the sole purpose of undertaking research (McDonald, 2001), and in such cases some form of 'beginning' and 'ending' will be involved even if the project itself is ongoing. The ending of PR as a distinct process could therefore be defined as a sixth phase of PR and will be considered as such for the purposes of this dissertation, in line with Northway's (1998) recommendations.

Figure 11: Maguire's framework for undertaking PR

Phase 1: Organisation of the project and knowledge of the working area

- This phase includes: gathering information about the research area and its central problems; establishing relationships with community groups; and inviting groups to participate in the research or responding to a request from the community.

Phase 2: Definition of generating problematics

- Facilitating a dialogue of problem-posing in order to explore co-researchers' perceptions of their most significant problems and issues.

Phase 3: Objectivisation and problematisation

- Attempting to link individual interpretations of problems to the broader social and structural context, for example via collective educational activities. This phase leads to the compilation of questions and themes to be investigated.

Phase 4: Researching social reality and analysing collected information

- Co-researchers design a research process to jointly investigate identified problems. Co-researchers are involved in gathering, classifying and analysing information, developing theories and solutions to the problems.

Phase 5: Definition of action projects

- Co-researchers agree on actions to be taken to address problems investigated.

(Source: Maguire, 1987:40-42)

Key design issues to be considered at the start of a research project include: selecting the research site and participants; negotiating access to the site and making agreements with participants; establishing an appropriate timeline for the research; identifying and implementing informed consent procedures, and dealing with related ethical issues; and establishing suitable approaches for recording data (Cresswell, 1998; Janesick, 1998). The way in which I addressed these design issues is highlighted in the following sections, commencing with description of the processes and rationale involved in my choice of research site. These initial negotiations and decisions constituted Phase One of the PR project undertaken.

Phase One: Organising the project

Process and rationale for selecting research site

I had a clear view from my review of literature on the nature of oppression and power in the lives of mental health service users, and on the emancipatory potential of PR, that I wanted to attempt to undertake PR with people who were not already members of an established, politicised group, such as a self-advocacy or user group, to explore the way in which PR might contribute to the development of empowerment processes for disadvantaged people who were not already involved in collective work of this nature.

I had contacts in mental health organisations in the West of England through my paid work, one of whom was a project manager for a recently established voluntary organisation project providing group support and activities to people with experience of mental distress. I knew that this manager had an interest in and appreciation of research issues, and that the project was local and therefore accessible for me (an important and valid consideration as I was undertaking full-time work at the same time) and so approached her about my proposed research. She was very enthusiastic about my proposal and felt that adopting a PR approach with people using the project would be an interesting and important process. The project was not undertaking any user involvement or participation activities with service users at the time, and I felt that a PR project might therefore be a valuable and beneficial resource for service users to access if they so wished.

The project was located in a relatively deprived area, with a complex range of socio-economic problems and high reported rates of mental distress amongst residents. I therefore hoped that PR's aim to produce practical benefits would be helpful for people living in this disadvantaged community.

My rationale for locating the PR project within this setting was therefore partly intellectual, in that I wanted to work with a group of people who were not already meeting and undertaking user involvement, participation or 'self-help' activities, and partly pragmatic, in that it was a local project which would be accessible to me (Punch, 1998)[110]. This latter point was an important consideration for me as a part-time doctoral student attempting to undertake PR, as the labour-intensive nature of PR work over a long period of time has been well documented (e.g. Maguire, 1987; Martin, 1994).

The 'host organisation'

I was also aware that choosing this voluntary organisation project as the research site would involve them acting as a 'host organisation' and therefore potential 'gatekeeper' of research participants (Cresswell, 1998; Homan, 1991). A tension was apparent between my theoretical and ideological perspective of people with experience of mental distress as autonomous, self-determining agents, and the need to communicate via such 'gatekeepers' to contact participants, negotiate conditions of access to the research site, and keep the PR project progressing smoothly in the light of the host organisation's potentially competing agendas.

The power relations that operate within any organisation, both the 'formal' official structural relations of hierarchy and reporting, and the informal power relations between staff and between staff and service users, were likely to influence the way in which our PR project progressed within this context (Thompson, 1998). An important part of my research design was therefore to ensure that clear information was given to both the manager and support workers about the PR project and the boundaries of their involvement with our PR group. When tensions arose with staff during the research process, I ensured that I met with them to address these

---

[110] The local nature of the project was important as I was employed full-time and therefore needed to minimise the amount of time away from work that I would be requesting from my manager.

promptly, to avoid disruption to the group's work (see p.255, for example). I also ensured that I carefully documented the way in which these organisational power relations operated and impacted upon our PR project, in order to make these explicit in my subsequent presentation of findings (as advocated by Humphries et al, 2001).

The local 'host organisation' was part of a national voluntary organisation supporting people diagnosed as having 'severe long-term mental health problems', their families and carers. I was also aware that tensions might arise between the national organisation's management and strategic objectives and those of the local organisation (Batsleer, 1995; Billis, 1993).

Similarly, the local organisation was contracted by the local authority's social services department to provide services, which I was aware might potentially lead to issues of 'co-optation' by statutory services (Batsleer, 1995) and "political dangers" (Reading, 1994:10) in terms of host organisation fears about being seen to be critical of the local authority if this became a focus of our PR group's action. Being sensitive to such potential tensions enabled me to address these as they arose during the PR project via the provision of clear and open information, and a reassertion of the purpose and boundaries of our PR group[111].

The local organisation had been established as one of four centres providing daytime group support in the area[112], to replace the previous central day centre operated by the social services department five days a week. Although the project explicitly stated that it provided 'drop-in' group support to distinguish it from the more traditional and institutionalised environment of the local authority-run day centre, in practice many of its activities were similar to those of the traditional day centre, for example opportunities for recreational and leisure activities in the company of other people (Davis, 1984). Such 'socially segregated' provision has been criticised for reinforcing social stigma and encouraging social withdrawal (Ridgway, 2001), which runs counter to the view expressed in this dissertation that mental health service

---

[111] These issues and tensions with regard to the host organisation's role will be described in more depth in subsequent chapters of this dissertation.

[112] At the time our research was taking place, the organisation's weekly provision included one daytime drop-in session for men and women, one women-only session, one evening drop-in session, and a weekly outreach session, as well as regular social trips to local places of interest.

users should be enabled to participate as full citizens in 'mainstream' society. Nonetheless, opportunities for contact and discussion with other people with similar experiences, to help combat loneliness and isolation, were clearly valued by users of the project, similar to the reported benefits of more traditional day care provision (Davis, 1984; Exell and Mayes, 2003). I felt that our PR project could provide further benefits of this nature for those involved, via opportunities for sharing experiences and undertaking reflection for collective action.

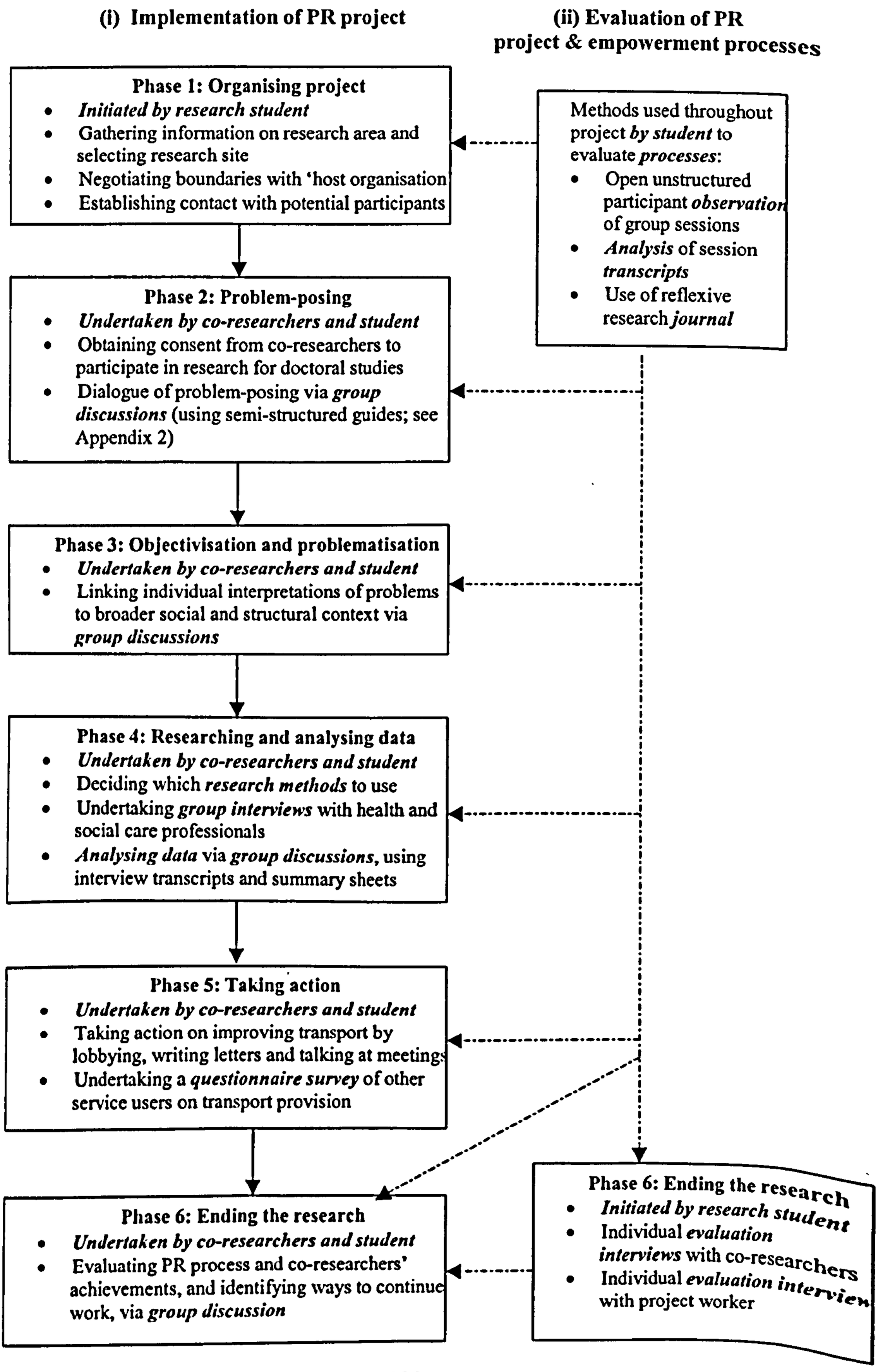
I was conscious that the benefits of our project might be limited if it were taking place within an environment which did not support similarly user-centred ways of working (Fitzsimons and Fuller, 2002). However, with a change of manager of the 'host organisation' near the start of our research, the organisation's ethos became more user-led and our project became supported by other initiatives to involve users more in decision-making and responsibility for the organisation's direction.

Elements of research design

There were two separate issues to address when designing this research project. The first was the design and implementation of the PR project itself, which was important to establish so that I was able to draw conclusions about the extent to which the research was participatory. These conclusions would then allow me to make observations about the extent to which PR processes might also entail processes of empowerment. These two elements are dealt with separately over the next two sections, with acknowledgement that some issues are common to both (for example establishing the group of co-researchers, ethical considerations, and the nature of research methods used). Figure 12 summarises the way in which these elements of the research design were inter-related and the research methods used, presented according to Maguire's (1987) phases of PR[113].

[113] It should be noted that although Figure 12 implies a linear, sequential research process, in practice phases overlapped and co-researchers moved backwards and forwards between phases throughout.

Figure 12: Elements of research design



Implementation of the PR project

Contacting participants

In line with Maguire's approach, the aim was to work jointly with a group of mental health service users as co-researchers at every stage of the PR process. Although Maguire initially undertook individual interviews with women before bringing them together in a group, I was concerned that such an approach might discourage people from participating, particularly as individual interviews could often have negative connotations of 'assessment' for mental health service users (Barnes, 1999b). I therefore felt that working in a group from the start was likely to be the most appropriate approach (although this was negotiated with the people who expressed an interest in taking part).

Due to the amount of time which co-researchers were asked to give to the PR project, participants were not 'sampled' in the way that might be expected in research adopting a positivist, experimental approach. Instead, the research was explained to all users of the local drop-in centre at a meeting (supplemented by clear written information: see Appendix 8) and they were invited to join the PR group being established[114].

I hoped to obtain a balance of participants with regard to gender, ethnicity and age, and a group size of five to six participants (Flick, 2002; Lee, 2001), and envisaged undertaking further recruitment were this not achieved via self-selection. However, the group which became the 'core' group of co-researchers did include both men (n=2) and women (n=4) of a range of ages, a participant whose first language was not English, and initially five and then six participants, and therefore further recruitment of participants was not considered necessary.

The group met 25 times over a period of eleven months, from May 1998 to March 1999. Although the group aimed to meet every week, other activities run by the local organisation and holiday periods meant that sessions took place less frequently than originally envisaged.

---

[114] This approach was similar to that advocated by Lee (2001) in relation to the formation of empowering groups, who identifies self-selection and individual choice as the usual method of formation for such groups.

Consent and ethical considerations

Ethics can be usefully defined as "the sets of moral principles which are held by members of a group" which "represent the active ownership and practice of... values" such as rights, reciprocity and empowerment (Everitt et al, 1992:60). Beyond such principles, being sensitive to ethical considerations and dilemmas throughout the research process is critical for researchers (Babbie, 2001; May, 1997). Indeed, Deyhle et al (1992:601) argue that researchers should strive to "act ethically" in all situations, with honesty, integrity, respect and confidentiality.

As both a postgraduate social research student and university contract researcher, I drew upon my training in research ethics, previous experience in research projects, relevant literature, the British Sociological Association's (BSA) statement of ethical practice and the British Psychological Society's (BPS) ethical principles for conducting research to obtain ethical guidance to inform my research design and practice.

At the time of establishing this research, the university did not have an ethics committee to which my proposal could be submitted for approval. As Homan (1991) notes, the system of ethical control common in many universities at the time for fieldwork carried out by students was for proposals to be screened and approved by their supervisor, as was the case with this research[115]. Nonetheless, I consciously attempted to ensure that my proposed research included proper consideration of ethical issues on the basis of guidance available to me at the time.

Key ethical issues commonly identified in social research include voluntary participation, no harm to participants, anonymity, confidentiality and right to privacy, no deception, and honest and accurate analysis and reporting of results (Cresswell, 1998; Homan, 1991; Punch, 1998). These all form part of conditions of consent which should be established at the start of the research project (Fontana and Frey, 1998) such that participants are agreeing to voluntarily participate in research

[115] It is acknowledged that the situation with regard to obtaining ethical approval for research projects is now different, with statutory agencies requiring more formal processes of ethical approval for all research projects involving health and social care agencies (Department of Health, 2001b), and with more university departments establishing formal ethical review procedures for all proposed research including that by students.

on the basis of "full and open information" (Christians, 2000:138). Explaining these issues in a way that participants can understand is also vital (Steel, 2004).

At the start of our PR project, I therefore spent time with co-researchers explaining issues of consent (such as those outlined above) and obtaining written consent from them to take part in the project (Appendix 1)[116]. I read through the consent form with the group, as one co-researcher stated that she had difficulty reading and writing. The issue that co-researchers seemed most concerned about was that their names would not be used or given to anyone, and they all appeared happy to sign the forms.

Obtaining informed consent at the start of the process is a sensitive issue in such collaborative research, as topics to be explored emerge from co-researchers as the study progresses and it is therefore inappropriate to define research areas in advance. In this sense, it has been suggested that consent should be seen as an emergent process, to be further negotiated with co-researchers throughout the project (Knox et al, 2000; Northway, 2000b). Indeed, Homan (1991) notes that such collaborative research procedures extend the concept of informed consent in that participants continuously review data collected from them and have the right to withhold permission for data to be used (as was the case in our project).

To honour the confidentiality and anonymity of co-researchers, they have been allocated pseudonyms in this dissertation, and minimal details have been presented about their backgrounds and circumstances to avoid the possibility of identification. The project worker has also been given a pseudonym and the name of the host organisation has not been included in this dissertation. With regard to confidentiality in data storage, all primary data sources were held securely by the researcher.

[116] In line with the BSA and BPS guidance, the consent form highlighted that they had the right to stop participating in the research at any point without having to explain why, that the discussions and interviews would be tape recorded but they could turn off the tape recorder at any time, that I intended to use information from these discussions and interviews in my doctoral dissertation and other publications but that participants' anonymity and confidentiality would be protected, and that they had the right to receive notes from our discussions and interviews and to add to or amend these as they wished.

Beyond issues of consent, other ethical considerations arise in research of this nature due to the different, 'non-traditional' role adopted by the researcher. Although it could be argued that the very ethos and value base of PR and other collaborative research approaches imply openness and honesty with co-researchers (Punch, 1998), it must nonetheless be acknowledged that power imbalances frequently characterise research relationships, and that the kinds of relationships established during participative research projects may give potential for exploitation despite PR's avowed aims to counter this (Swantz and Vainio-Mattila, 1988).

Due to its longitudinal nature and the values inherent in its practice, PR tends to involve the development of relationships between co-researchers, which tend to "permit and necessitate deeper personal disclosure on the part of both researcher and researched than is the case in other forms of research" (Deyhle et al, 1992:619). Key ethical questions therefore relate to how such relationships are structured and how information is gained and disclosed (Deyhle et al, 1992). For example, people may reveal sensitive information about themselves which could potentially cause psychological harm (Babbie, 2001), implying the need for a researcher to be able to respond appropriately to such disclosure, including possible referral to other sources of support if desired (for example, via the voluntary organisation support worker in our project).

How the researcher presents her/himself to research participants is also important, in that disclosing personal information may cause participants to feel obliged to do likewise even if they feel uncomfortable. I attempted to address this ethical issue by being open with participants about my experiences, views and feelings when they asked me to do so but otherwise taking a 'back seat' in discussions to enable co-researchers to direct these, so that I consciously attempted not to use my own experiences to trigger discussions or to prompt co-researchers to divulge personal information.

The heterogeneous nature of any group, and the inequalities, differing needs and values therefore likely to exist, also involve ethical considerations for a researcher (Dullea and Mullender, 1999; Kelly, 1993), who is required to manage such dynamics carefully (Dominelli, 2002).

Obtaining a balance between encouraging people to participate and raising hopes which cannot be met is an ethical issue in PR (Cornwall and Jewkes, 1995; Packham, 2000). This relates to reciprocity, i.e. participants obtaining benefits from taking part in research, possibly in the form of information or services (Deyhle et al, 1992). PR explicitly aims to foster such benefits, with its emphasis on knowledge generation and sharing, and on taking action to improve people's circumstances, and can therefore be said to be an 'ethical' research approach in this sense (and potentially more 'ethical' than traditional research which, while not harming participants, does not usually result in any direct benefits or improvements in their circumstances).

Potentially negative consequences of PR, such as endangering an empowered group which decides to challenge existing power structures, should also be considered (Cornwall and Jewkes, 1995). In such cases, it is important that people participate voluntarily in the research, and that the researcher is open throughout the project about possible consequences of their participation and the research's limitations (Homan, 1991).

Ending a PR project also involves ethical considerations, particularly as relationships and expectations of ongoing benefits are likely to have been established (Deyhle et al, 1992; Punch, 1998). I was very conscious of this ethical issue, and in addition to being clear at the start that the project was likely to last for a maximum of one year (due to the requirements of my study timescale), I also endeavoured to link our PR project into the 'host organisation' via the support worker and via user involvement and participation activities occurring in the drop-in centre, so that activities might continue beyond the life of our project.

Research methods

PR projects tend to use a mixture of research methods. Swantz and Vainio-Mattila (1988:133), for example, used what they describe as "traditional tools of anthropological field research... formal and informal interviews, free communication, and observation, both participant and direct" in their PR work.

Qualitative methods

This project used primarily qualitative methods, considered to be particularly appropriate due to the nature of the research aims, the values underpinning the research, and the complex personal, interpersonal and social processes being explored (Ridgway, 2001). Several themes of qualitative research have been identified by Patton (1990), all of which can be seen to some degree as congruent with PR's ethos and the issues under consideration. These themes are summarised in Table 6.

Table 6: Themes of qualitative research

Theme	Description
Naturalistic inquiry	Non-manipulative, unobtrusive and non-controlling; openness to whatever emerges – lack of predetermined constraints on outcomes
Inductive analysis	Immersion in the details and specifics of the data to discover important categories, dimensions and interrelationships; begin by exploring genuinely open questions rather than testing theoretically derived (deductive) hypotheses
Holistic perspective	Focus on complex interdependencies not meaningfully reduced to a few discrete variables and linear, cause-effect relationships
Qualitative data	Detailed, thick description; inquiry in depth; direct quotations capturing people's personal perspectives and experiences
Personal contact and insight	The researcher has direct contact with and gets close to the people under study; researcher's personal experiences and insights are an important part of the inquiry and critical to understanding the phenomenon
Dynamic systems	Attention to process; assumes change is constant and ongoing
Unique case orientation	Assumes each case is special and unique; the first level of inquiry is being true to, respecting and capturing the details of the individual cases being studied
Context sensitivity	Places findings in a social, historical and temporal context; dubious of the possibility or meaningfulness of generalizations across time and space
Design flexibility	Open to adapting inquiry as understanding deepens and/or situations change; avoids getting locked into rigid designs that eliminate responsiveness; pursues new paths of discovery as they emerge

(Source: Patton, 1990:40-41)

The interpretative, holistic, multi-method and flexible nature of qualitative research (Denzin and Lincoln, 1998; Janesick, 1998) is clearly valuable when undertaking a PR project. The use of qualitative methods is also validated by Rifkin et al (2000:31), who argue that qualitative methods are particularly important in PR due to their reliance upon and subsequent promotion of interaction between people, and to their value in supporting participation (for example by generating ownership of information, and by focusing on problems defined by participants).

Qualitative methods used to implement and monitor this PR project and potential empowerment processes occurring were group discussions, individual interviews, and observation. This combination of multiple methods contributed to obtaining a more in-depth understanding of issues being explored (Denzin and Lincoln, 1998).

Group discussions

The group sessions involved group discussions, facilitated by myself and supported by the voluntary organisation worker. These sessions were used to work through the phases of PR identified by Maguire, and semi-structured guides were developed for each session (Appendix 2) (although these were not necessarily followed if co-researchers wished to focus on other issues).

Such group discussions, where participants may already know one another, have been identified as more 'natural' than formal focus group interviews, and may therefore allow for an easier flow of information (Rifkin et al, 2000) similar to discussion in 'real-life' situations (Flick, 2002). Indeed, by encouraging interaction between group members, such discussions encourage people to "stimulate each other to recall different incidents and express views" (Ovretveit, 1998:204), and also enable a researcher to observe processes of interaction (including power relations) between group members (Madriz, 2000).

Group discussions may also be experienced by participants as less intimidating and therefore 'safer' than one-to-one interview situations (Madriz, 2000; Ovretveit, 1998). In the context of PR, the interactive group format may facilitate increased control of the direction and content of discussion (Madriz, 2000).

Limitations of such group discussions include that "it is often less easy in a group to probe and follow up one person's views, and there may be a greater pressure to express views which a person thinks are acceptable to the group" (Ovretveit, 1998:204). Particular aspects of my role during these group discussions, therefore, were to manage group dynamics and to encourage participation by all co-researchers (Cresswell, 1998; Fontana and Frey, 1998).

The sessions were tape recorded, with the group's permission, and transcribed in full. To adhere to PR's commitment to information sharing and knowledge creation, each discussion session was transcribed weekly to produce a full transcript and summary document for co-researchers the following week.

Individual interviews

At the end of the project, individual evaluation interviews were conducted with the co-researchers and project worker. Interviews are a valuable way to access people's views, feelings and recollections of experiences and interventions, both with regard to processes and outcomes (Ovretveit, 1998). Semi-structured interview schedules were used to undertake these interviews (Appendices 3 and 4), to give direction while also allowing space to follow leads as they arose (Rifkin et al, 2000).

Limitations of such interviews are acknowledged, including that interviewees may only recall selective elements of events (although it could be argued that such selection may reflect what was important to people about those events), or give answers according to what their perceptions of the interviewer's 'desired' responses (Mason, 2002; Ovretveit, 1998). Attempts were made to minimise such bias by explicitly including questions on the project's weaknesses and ways in which it might have been improved.

Individual interviews tend to yield most data from people who are confident to speak out and share ideas in such a situation (Cresswell, 1998), and it is acknowledged that the extent to which co-researchers felt comfortable doing so in this situation varied (see p.306). Nonetheless, these interviews were a rich source of data in relation to

identification by co-researchers (and also by the support worker) of elements of the PR process which had been empowering in different ways[117].

Observation

Participant observation has been identified as a central technique of qualitative research (Punch, 1998), whereby "the researcher is involved in activities with the people in the community of investigation" and "the people are aware of the purpose of the researcher and to varying degrees are aware observations are happening" (Rifkin et al, 2000:111). In the sense that I was participating in the group with co-researchers undertaking joint research, while also observing and analysing the way in which this group was developing and processes were occurring, I could be defined as a 'participant-observer'[118]. Such an observational approach has been used in other qualitative process-focused studies (e.g. Frankel, 1982; Heinz and Grant, 2003).

Identified strengths of participant observation include that it facilitates understanding of the values, norms, events, cultural contexts and language of the participants, and enables the discovery of information "hidden from public view" as the group becomes comfortable with the researcher (Rifkin et al, 2000:111-112).

Different forms of observation include pre-structured and coded observation, and 'open' unstructured observation which involves carefully recording all conversations and situations (Ovretveit, 1998:201). I used the open unstructured form of observation as I did not wish to impose my own set of predefined categories on co-researchers' views and behaviours, and wanted to be open to considering the situation and processes occurring in all their dimensions rather than focusing on one particular issue. Due to the nature of this research as a doctoral study exploring power and empowerment processes, I was aware of certain conceptual frameworks which might be applicable to the data obtained, but I wanted to allow categories to emerge inductively from the fieldwork data (which I could then compare to these conceptual frameworks to assess the extent to which they corresponded).

---

[117] Findings from these interviews are presented in Chapter Ten.

[118] It is acknowledged that participant observation involves a continuum with regard to the extent of participation in the situation, and to the overt or covert nature of the observation (Atkinson and Hammersley, 1998; Patton, 1990).

Use of reflexive research journal

In line with recommendations from colleagues and the PR and qualitative research literature, I kept a reflexive journal throughout the process to regularly record my observations, interpretations, feelings and views about events and processes occurring[119] (Cresswell, 1998; Fontana and Frey, 1998). Reflexive journal writing has been identified as a research technique in itself, valuable as a data source for reflections on the researcher's role and the research process (Adams, 2003), and hence contributing to triangulation of data (Hammersley and Atkinson, 1995). Journal writing can also help to improve research practice via reflection, thereby implying an action research element (Janesick, 1999).

Reflexivity has been highlighted as a critical attribute of qualitative and participatory researchers (Lincoln and Guba, 2000; Northway, 2000b) in their relationship to the research process, context and participants (Davis, 2000; Truman, 2000), particularly in the light of unequal power relations between participants, researchers and their institutions (Kemshall and Littlechild, 2000; Wallerstein, 1999). It is important that researchers acknowledge the power imbalance between themselves and the people with whom they are working (George, 1996), and are explicit about "how power relationships are negotiated within the course of their fieldwork and what steps are taken to reduce the authority of the researcher" (Davis, 2000:203).

Secondary analysis of background documentation

Background documentation was also collected on the local voluntary organisation and the community in which it was based to contextualise the PR project.

In addition to the methods which I instigated to implement and monitor the PR project, co-researchers themselves chose and used research methods to explore areas of interest identified via group discussions. These methods were group interviews and a questionnaire survey.

---

[119] This journal is drawn upon in Chapters Seven to Ten in order to provide a fuller picture of the research and also to locate myself within this analysis in line with PR's emphasis on critical reflexivity by the researcher.

Group interviews

Following exploration of co-researchers' experiences and interests, and of possible research methods to use to explore issues identified, co-researchers chose to carry out group interviews with health and social care professionals (described in Chapter Eight). Three interviews were conducted by the whole group of co-researchers using a topic guide agreed in the group, developed from discussion of their experiences and concerns (Appendix 5). My role (as requested by co-researchers) was to 'chair' these interview sessions. The interviews were transcribed in full and summarised, to provide a basis for analysis and subsequent action with co-researchers.

Questionnaire survey

Some quantitative work was also undertaken by co-researchers. As part of action on transport provision[120], the group undertook a questionnaire survey of other drop-in centre users (n=23). Questionnaires are seen as valuable data collection tools where data about a specific topic, which has a similar meaning and is well understood by a group of people, is required (Ovretveit, 1998). The questionnaire used for this survey (Appendix 6) was based upon ideas discussed and agreed by co-researchers, and contained mostly closed questions with fixed responses together with some open questions to allow participants to express their views. Analysis of questionnaire data was undertaken with co-researchers.

Evaluation of empowerment processes

PR approaches have been defined as empowering by other researchers (e.g. Fitzsimons and Fuller, 2002; Papineau and Kiely, 1996; Swantz and Vainio-Mattila, 1988). Therefore, in addition to the way in which this PR project was implemented and monitored, my research design aimed to address the way in which the nature and extent of empowerment processes occurring might be evaluated.

[120] Detailed in Chapter Nine.

Rationale for evaluation approach adopted

My literature review of paradigmatic and epistemological stances in research, methodologies, and critiques of positivist experimental research as alienating and oppressive, led me to feel very uncomfortable with the idea of using a pre-defined, closed-category, quantitative measurement tool such as a psychological scale to evaluate the extent to which PR might function as a strategy of empowerment for people with experience of mental distress.

It can be argued that use of such a tool to undertake 'pre-' and 'post-intervention' measurement of empowerment 'levels' would be an inappropriately superficial approach to exploring the complex processes involved in empowerment (Adams, 2003:149). Indeed, the use of quantitative outcome indicators to evaluate participatory projects has been identified as limited due to difficulties in quantifying participation[121] (Rifkin et al, 2000; Schulz et al, 2003). Furthermore, in order to be sufficiently 'rigorous' as defined within the positivist paradigm, such an approach would require the establishment of 'intervention' and 'control' groups of research 'subjects' to demonstrate that any changes in empowerment 'levels' were a direct result of our PR project rather than of any other activity or change occurring (Frankel, 1982; Ovretveit, 1998).

As outlined in Chapter Five, I considered such a research approach to be inappropriate for exploration of the issues under consideration with the proposed group of people, and wanted to work in a more innovative and participative way to explore people's views and experiences in their own terms. Committing to undertake a PR project, and then using an experimental positivist approach to evaluate processes occurring within that project, would have been an intellectual and ideological contradiction, particularly in the light of arguments developed in this dissertation. I did not want to contribute to the body of oppressive scientific mental health research which has imposed categories of explanation upon people, silenced their voices, and reduced their experiences to a set of measurable variables.

---

[121] For example, such outcome indicators are only likely to be able to demonstrate *what* happened (e.g. presence at a meeting) and not *how* or *to what extent* participatory processes were occurring (e.g. active participation in meeting) (Rifkin et al, 2000).

In the context of developing more empowering approaches to mental health research and practice, Fitzsimons and Fuller (2002) advocate "a more action-based attempt to understand the interaction of a variety of variables in a real life setting, embracing, rather than trying to control for... subjective perceptions, cognitions and interpretations" (p.485-486). Furthermore, outcomes of an empowering process may take several years to occur (Baistow, 1994), making such outcome measurement inappropriate in a time-limited project.

On the basis of these considerations, I felt it more appropriate to adopt a process evaluation approach to considering the nature and extent of empowerment occurring during PR (as advocated by Adams, 2003), using exploratory, open qualitative research methods which would allow 'thick description' of the subtle and complex empowerment processes likely to be operating[122]. This decision has subsequently been reinforced both by Fitzsimons and Fuller's (2002) review which concluded that a focus on outcome variables with regard to empowerment would be likely to ignore important process aspects, and by Rifkin et al's (2000) favouring of qualitative process approaches to evaluating participatory projects to capture the complexities of change processes.

The importance of evaluating dynamic change via process-focused research is also highlighted by Langley et al (2003), as it allows researchers to "examine sequences of events directly in order to understand how and why entities evolve in particular ways over time" (p.196). To undertake such process research, they advocate the use of a small-sample longitudinal research design, as was the case in our PR project.

Evaluating empowerment processes

As argued in Chapter Three, a view of empowerment as some form of outcome of an intervention risks oversimplifying this complex concept and ignoring the richness of process aspects of empowerment. Most authors writing on this subject have tended to define empowerment as a dynamic and fluid process operating at different levels and varying according to context and time span (see p.85-88). From my review of

[122] This approach was similar to that used by Papineau and Kiely (1996) in their participatory evaluation project.

the literature available at the time of designing this research project[123], I concluded that individual empowerment could most usefully be viewed as an ongoing process of personal growth and development. Empowerment processes might then include people:

- enhancing their sense of personal power, control, confidence and self-esteem;
- developing a more positive self-definition;
- obtaining desired information;
- enhancing their skills and abilities; and
- asserting their personal needs and influencing the ways in which these are met to achieve improvements in their personal circumstances.

With regard to group empowerment, available literature suggested that this might entail processes of collective consciousness-raising via sharing experiences, joint participation in social or political action, and working to achieve some redistribution of resources or decision-making in favour of the group, in addition to processes of individual empowerment for group members (see p.88).

I therefore used these operational definitions of individual and group empowerment to sensitise myself to potential empowerment processes occurring during our PR project, and to guide my observation notes, interviewing and data analysis. From the first group session, I took detailed notes on each co-researcher's comments and actions including, for example, their participation in the group, power relations operating, and expressed and observed elements of empowerment and disempowerment.

However, it should be emphasised that I considered these operational definitions of empowerment to be informative rather than prescriptive in relation to the research design. Fitzsimons and Fuller (2002) highlight "the need for researchers to be sensitive to the meaning of empowerment in a particular setting since the meaning of

[123] Literature reviewed was that published up to 1997: for example, Dalrymple and Burke, 1995; Gaster, 1996;

personal control and the nature of resources and goals defined as important can vary" (p.487). In line with PR's ethos, I decided not to impose any preconceived categories or definitions of empowerment on co-researchers and did not introduce such discourse into our discussions, consciously striving to ensure that experiences, themes, language and terms of reference used were those of the co-researchers (Alverson and Becker, 1995). Similarly, in individual evaluation interviews, I consciously asked open, general questions about 'benefits' and 'learning' rather than specific questions on empowerment and elements thereof.

In these ways, I hoped that PR processes (and potentially empowerment processes) would be allowed to occur 'naturally', without distorting these by introducing academic, researcher-defined terminology and frameworks for understanding experience (which may have been experienced as alienating by co-researchers). This approach has subsequently been vindicated by Adams (2003:144-145), who argues for the importance of allowing participants to define their own situation and the value of supposedly empowering activities, even though their comments might not be capable of being 'objectively validated'.

Furthermore, rather than using definitions of empowerment (and of power and oppression) from the literature to develop a pre-coded categorical framework for analysis (as would be done in a hypothetico-deductive research approach) (Ovretveit, 1998), data analysis was inductive (see p.207), with categories and themes allowed to emerge from the data (Papineau and Kiely, 1996). These categories and themes were then compared with those from the literature to assess the extent to which they corresponded with previous writing on empowerment processes, and to see whether different process elements which might be considered empowering also emerged during our PR project. In this way, I hoped to avoid 'narrowing' down description of co-researchers' experiences and to allow their voices to be fully heard.

Rappaport, 1987; Staples, 1990.

Research methods

As highlighted above, research methods used to evaluate empowerment processes occurring in this project included participant observation, individual interviews, and ongoing description and analytic field note taking in my reflexive journal.

Data analysis

Two levels of data analysis were required in this work, as both a PR project and a doctoral study. Data analysis was undertaken throughout the PR project with co-researchers, as we reflected each week upon data generated in previous sessions and used these as a basis for further reflection and action[124]. These data analysis processes are referred to in Chapters Seven to Nine, and correspond to the "cyclical process in which data is *(sic)* analysed, studied and interpreted as it is collected" described by Ellis in her PR project (1990:25).

In addition, to meet the research aims, analysis of the implementation of the PR project itself and of empowerment processes occurring is presented. The following section describes my approach to undertaking this data analysis.

Data analysis in PR

The PR literature includes little commentary on how data analysis is conducted. De Koning and Martin's (1996b) edited collection on PR and health, for example, contains no explicit discussion of data analysis. Maguire's (1987) description of her PR project does not include discussion of how she undertook data analysis for her doctorate. This reinforces Denzin's (1994) criticism of critical inquiry methodologies such as PAR as "they foreground praxis, yet leave unclear the methodological side of the interpretive process" (p.509).

This omission may relate to PR's strong emphasis on action, but it is nonetheless important to have well developed and explicit approaches to data analysis to enhance the credibility of PR's findings. If PR is to be distinguished from activities such as community development and social work practice (see p.174-175), the analytical

---

[124] This was similar to the process of analysis for action described by Kemmis and McTaggart (2000) in their PAR project.

dimension is important. This study therefore aims to contribute to the development of PR methodology in this respect.

Qualitative data analysis

As there is little commentary on data analysis in PR literature, and primarily qualitative methods were used in this fieldwork, literature on qualitative data analysis has been drawn upon to establish an analytical framework for this dissertation.

Common processes in qualitative data analysis can be identified, despite the diversity of research 'traditions' involved. Analysis of qualitative data tends to be inductive, i.e. it "seeks to build up categories of meaning out of the data" (Ovretveit, 1998:199) such that categories are defined after rather than before data collection. Miles and Huberman (1994:10), in one of the most often-cited textbooks on qualitative data analysis, identify three "concurrent flows of activity" in analysis, namely data categorisation and reduction, data display, and conclusion drawing and verification.

'Framework' is a data analysis approach, developed and extensively tested by Social and Community Planning Research[125], which neatly exemplifies the process described by Miles and Huberman and entails five distinct but interconnected stages (Table 7, p.208).

The 'Framework' approach is a well-tested way of systematically analysing qualitative data, and incorporates all aspects of Miles and Huberman's recommended phases of analysis. This approach was therefore used to carry out data analysis for this dissertation.

[125] SCPR has now been renamed the National Centre for Social Research.

Table 7: The 'Framework' qualitative data analysis approach

Stage	Description of process
Familiarisation	Immersion in the whole body of data via immersion, reading all transcripts and notes and listing key ideas, recurring themes, and key aspects of the research process
Identifying a thematic framework	Returning to the data to identify key themes and issues and constructing a thematic index based upon "a priori issues (those informed by the original research aims and introduced into the interviews via the topic guide), emergent issues raised by the respondents themselves, and analytical themes arising from the recurrence or patterning of particular views or experiences" (p.180)
Indexing	Applying the thematic framework and annotating all data using indexing references in the transcript margins[126]
Charting	Taking data from the data set and rearranging in summarised form in charts (e.g. matrices) according to the thematic framework
Mapping and interpretation	Drawing together all key characteristics of the data, identified via their thematic charting, in order to map and interpret the whole data set systematically

(Source: Ritchie and Spencer, 1994:180-186)

Group data analysis

There is a paucity of discussion on how to analyse data collected from groups, for example via group discussions or interviews, within the qualitative research literature. The exception to this is the growing literature on focus group methods (e.g. Frankland and Bloor, 1999), although this also fails to provide much detail on analytical processes and techniques specific to groups.

One of the main differences between analysing qualitative data obtained from individuals and from groups is the need to analyse group interaction (Kitzinger and Barbour, 1999). This distinction was important to bear in mind during analysis, and

[126] More than one researcher is often used to carry out indexing to enhance validity, but such an approach is difficult in the context of doctoral studies.

relates to Hammersley and Atkinson's (1995) emphasis on taking account in analysis of the social and temporal contexts in which data are produced.

Approach to data analysis adopted

Suggested framework for data analysis

As Maguire's (1987) five-stage framework for conducting PR was followed in the design of this project, it has been used to present research findings in this dissertation. An additional sixth phase, on ending the research, has also been included. Reporting of each phase includes brief description of the sessions and interpretation of the data, analysed inductively using the 'Framework' approach described above[127].

Existing data analysis frameworks could not be identified in the PR literature, and I therefore drew upon what literature was available to develop my own approach to data analysis. In line with the research aims, data have been framed within the relevant theoretical and empirical literature reviewed earlier in this dissertation and presented within each chapter under the themes of: people's experiences of oppression and power relations; processes of power and empowerment in PR; and PR methodological principles in practice[128].

PR involves two sources of knowledge, namely co-researchers' experiences and views, and the views and comments of people interviewed or canvassed as part of the 'research' phase. The PR literature does not sufficiently draw out these different sources of knowledge production, but both have been included in the analysis of this project.

Gaps identified in the qualitative data analysis literature include how to analyse group data (see p.208), and how to undertake longitudinal analysis. These issues have been addressed in this dissertation by explicitly focusing on developments in group dynamics during each phase of the research process, and by presenting data in a similar format for each of these phases.

---

[127] See Appendix 7 for the thematic framework developed.

The way in which research participants' voices are presented in texts is acknowledged as problematic (Olesen, 2000), in that the researcher writing up the account is clearly in a powerful position. There is also a tension between treating participants' words as 'raw' data and critically analysing them with regard to the contexts in which they arose (including power relations operating). I have endeavoured to present co-researchers' experiences and opinions using their own language and definitions to value their knowledge and voices (Alverson and Becker, 1995). However, requirements of doctoral study have also led me to interpret their discourse in the light of theoretical and conceptual frameworks (e.g. of power and empowerment). It is acknowledged that in doing this, people's experiences are being 'repossessed' "as an academic subject that can be studied from the outside" (Reason, 1998:263).

The researcher voice is present throughout the analysis, allowing me to be explicit about my experience and about my relationship both to the co-researchers and to the research process itself, "an integral part of qualitative inquiry" (Wolcott, 1990:19). I have also used my reflexive journal both to inform the analysis and to keep explicit records of the rationale for decisions made during analysis.

An important ethical consideration in the analysis and reporting of data is that researchers should highlight the limitations of their work and negative findings, as well as its strengths and positive findings (Babbie, 2001; Deyhle et al, 1992; Fontana and Frey, 1998). I have attempted to do this throughout the following chapters, to ensure that I am open in my account of events occurring.

Data sources and triangulation

Data sources drawn upon include: group session transcripts; summary sheets for group sessions; plans for group sessions; transcripts of group interviews; correspondence and notes from conversations (e.g. with the project worker) between group sessions; my reflexive journal; and transcripts of evaluation interviews with co-researchers and the project worker.

[128] It should be noted, however, that differing emphasis is given to each theme in Chapters Seven to Nine depending on their relative prominence within each phase of the project.

This wide range of data sources has been used to triangulate data as far as possible (Janesick, 1998; Rifkin et al, 2000), as advocated by Tolley and Bentley (1996) in relation to PR. With regard to triangulation, Denzin and Lincoln (1998) argue that "the combination of multiple methods, empirical materials, perspectives and observers in a single study is best understood... as a strategy that adds rigor, breadth, and depth to any investigation" (p.4).

Conclusion

The research design for this doctoral work was developed by careful consideration of the PR methodological framework outlined in Chapter Five and ways in which this might link to proposed strategies of inquiry. My choice of research site had both an intellectual and pragmatic basis, and involved acknowledging and planning to address the tensions inherent in undertaking research in a voluntary sector day service context. Detailed ethical considerations to ensure that the research was undertaken appropriately and sensitively, with maximum benefit accruing to participants (my 'co-researchers'), underpinned my research design decisions and their subsequent implementation.

To meet the aims of this research, two distinct elements were required in the research design: implementation of the PR project itself, and the extent to which PR might entail processes of empowerment. For both of these elements, primarily qualitative methods of group discussion, interviewing and observation were chosen in order to explore and understand people's experiences and their ascribed meanings (Ovretveit, 1998).

Both elements involved a deliberate focus on processes rather than outcomes, to avoid oversimplification of the subtle and complex personal, interpersonal and social processes operating which might have occurred had quantitative outcome indicators been adopted (Papineau and Kiely, 1996; Ridgway, 2001). It is argued that this multi-method, process-orientated approach enabled the complexities inherent in each research aim to be explored and sensitively addressed, in a way that was in line with the ethos and values underpinning the research project.

As existing data analysis frameworks could not be identified in the PR literature, an innovative approach to data analysis was developed for this research, drawing upon literature on qualitative data analysis and group data analysis. The framework used for systematic analysis of the range of data sources was chosen as it was well tested in the context of qualitative research analysis and clearly exemplified the systematic data analysis processes outlined by other authors.

With regard to the research aim of highlighting issues for methodological development arising from the practice of PR, it is important to consider the gaps between PR theory and practice (Martin, 1996). Such analysis will be undertaken throughout the four following chapters, as description and critical analysis of the PR project is presented.

The next chapter therefore presents findings from the first phases of this PR project, analysed in the context of theoretical and empirical literature reviewed in earlier chapters.

Chapter Seven: Exploring Experiences and Posing Problems

Introduction

This chapter outlines the latter part of Phase One (continuing from discussion in Chapter Six), and Phases Two and Three of our PR project. With regard to Phase One, details are presented on: establishing contact with potential co-researchers and attracting them to participate; group interaction and participation in the first session; and PR methodological principles in practice. Phase Two involved identifying and exploring "participants' perceptions of their most significant problems" (Maguire, 1987:41), while Phase Three aimed to "link participants' individual interpretations of problems to the broader context, including the structural conditions of social reality" (ibid.).

After a brief description of participants, their attendance at sessions, and session content, findings from Phases Two and Three are analysed according to the themes of: the nature of oppression and power experienced by mental health service users; processes of power and empowerment in PR; and PR methodological principles in practice. Analysis is presented via the theoretical and conceptual frameworks developed to meet the aims of these doctoral studies. It is acknowledged that these are my interpretations of co-researchers' experiences, which may be different to their own. Nonetheless, I am presenting findings in this particular analytical way for a specific, academic audience.

It is also important to note that I am using pseudonyms for the co-researchers and project worker throughout, to preserve anonymity. Due to PR's emphasis on dialogue as a means of knowledge generation, and the importance of group interaction in fostering empowerment (Lee, 2001), some quotations presented are sections of dialogue from group discussions.

Establishing contact with the group

This section presents details of the way in which I attracted people to join our PR group (the latter part of Phase One).

The initial meeting with centre users

Soon after my initial meeting with the host organisation manager, she left the organisation. However, one of the project workers (referred to as 'Sue' throughout this dissertation) had agreed to take the PR project forward, and I arranged with her to attend one of the drop-in centre's weekly 'open meetings' with service users to present my research proposal. I also provided an information sheet on the proposed research for her to discuss with service users before this meeting[129].

There were ten people present at the 'open meeting' I attended (four men and six women). Sue was also present, with a sessional worker, and introduced me as attending to talk about the 'advocacy project' they had discussed[130]. Some people stated that they did not fully understand what the project was. I therefore talked about: my background and personal reasons for undertaking the project; examples of the sorts of issues that the group might decide to research, such as GP services, housing, employment or transport[131]; and practical issues about how the research process might work, for example that we would share experiences to identify issues we wanted to do something about and then work together to obtain evidence about those issues.

It was a difficult meeting, as there was limited interaction. One man (who went on to become a co-researcher) spoke about not being listened to by GPs, but most people present did not contribute. The workers asked me questions and seemed keen, but it was difficult to gauge levels of interest amongst the group.

---

[129] Deciding how much information to include in this sheet was difficult, as I was trying to follow PR principles by not suggesting concrete topics and processes for the project, aiming to allow these to emerge from the service users.

[130] Sue was describing my proposal as an 'advocacy project', an interesting reflection of her interpretation of PR, yet she also commented to me that most centre users had a limited understanding of what 'advocacy' actually was.

[131] Sue had told me that transport was an issue for service users there as people were having difficulties accessing the local council-subsidised transport service to travel to the drop-in centre.

Negotiating how to take the project forward

Discussion with Sue during the meeting break helped to alleviate my anxieties about attracting people to participate in the research. For example, she noted that they were a relatively new group who did not know one another well, which may have contributed to their 'quietness'.

We went back into the meeting, and two men stated that they would like to take part in the research but still did not fully understand what I wanted them to do. One in particular kept asking what information I wanted from them (possibly a reflection of their perceptions of research whereby 'outsiders' take information from them). I left with Sue having said that the first group meeting would take place on 12th May, and that people could choose to attend if they wanted to.

Prior to the first group session, I met again with Sue to explain how I envisaged sessions might run. The key message to emerge from our discussion was the need for flexibility, both with regard to the project's length and activities involved. Sue felt that it was hard to predict in advance how much service users would engage with the research, as it was more in-depth than any work previously done at the centre.

Attracting co-researchers

Despite my anxieties that no-one would choose to attend, seven people participated in the first PR group session, with a good gender balance (three men and four women). This was an introductory session, focused on getting to know one another, and therefore involved introductions and interactive exercises. I felt this was particularly important as I had established that co-researchers did not know one another very well.

I made a brief input on the project, using a handout I had produced (Appendix 8) that was much simpler than my original handout. I read through the handout, paying attention to the woman whose first language was not English as she expressed difficulty reading.

We also undertook some work on ground rules for the group, based upon those that the 'open group' had agreed a few months earlier[132] (as a useful starting point from which to develop our own list as group members were already familiar with these). However, ownership of the suggested ground rules by the group felt quite limited, and I decided that I would return to review them as the group became more established.

Group interaction and participation

Although some of the group were quiet, particularly the woman whose first language was not English, others seemed keen to participate and relatively comfortable being in a group with people they did not know very well. I was very pleased with the first session's progress, particularly as participation and interaction between people present were better than I had hoped for. The atmosphere was positive and the group felt quite safe for people to express themselves.

During the session, one of the men (Mike, who went on to become a core co-researcher) started to raise issues, stating that local services were "terrible" and "seriously lacking". He also asked me whether this group would be able to change anything. I said that I hoped it would be possible to achieve something locally, even if not on a 'grand scale'.

PR methodological principles into practice

I found it difficult to think about how to present the project in my initial approach to service users. PR methodology suggests that ideas and problems should come from the community (Park, 1993), yet it was hard to give people a clear idea of what the project might involve without 'leading' them too much on issues that might be important.

---

[132] These ground rules included: encouraging people to 'own' their opinions; establishing the right to withdraw from sessions, and to be involved at a level that was comfortable; and asking people to keep to time in the

The group's participation in the initial phase of planning the project was limited, in that the project was driven more by the project worker than by the service users in these early stages (although people were clearly offered the choice of whether to participate and did self-select into the project). For example, our group sessions took place more regularly than I had intended (and would have liked in terms of my time availability), largely due to the way the host organisation structured its activities in blocks with weekly sessions. As this was how centre users were accustomed to working, this was agreed as the format for our sessions. Hence this initial negotiation took place with the host organisation rather than with co-researchers, although I did renegotiate this timing with co-researchers once the group was established.

Exploring experiences and posing problems: Phases Two and Three

This section includes brief details on the co-researchers, their attendance at group sessions, and session content. Data from group discussions is then critically analysed, using the thematic framework derived from the research aims (outlined on p.213).

Participant details

Of the seven people who attended the first session, only three returned for the second session[133]. There were therefore two women and one man from the first session (Sheila, Maria and Mike) and two additional women (Rose and Amy) who had decided that they wanted to join the group. This became our 'core group' of co-researchers.

Brief profiles of co-researchers are presented in Table 8 to contextualise subsequent discussions[134]. I have not included people's psychiatric diagnoses of 'mental illness' as I never asked for this information and consider such labels to be oppressive and misleading (as discussed in Chapter One).

---

groups.

[133] Sue had not heard from three of the people from the previous week who did not return, and informed me that the fourth person was no longer going to be attending the drop-in centre on Tuesdays.

[134] The sharing of these personal details was agreed with co-researchers in evaluation interviews.

Table 8: Profile of co-researchers

Name of co-researcher (pseudonym)	Approximate age	Ethnicity
Amy	Late 20s	White British
David (joined from Session 12)	Early 60s	White British
Maria	Late 40s	White Southern European
Mike	Early 50s	White British
Rose	Early 60s	White British
Sheila	Early 50s	White British

Attendance of co-researchers at group sessions varied throughout the project, for a variety of reasons, including periods of feeling unwell, holidays and other appointments. Similarly, the project worker was not always present. These attendance patterns, and corresponding group sessions, are presented in detail in Appendix 9. It can be seen that co-researchers' levels of attendance at the 25 group sessions varied considerably, as summarised in Table 9:

Table 9: Summary of group member attendance at sessions

Name	No. of full sessions attended	No. of part sessions attended	Total no. of sessions at least partially attended
Mike	20	0	20
Rose	12	7	19
Sheila	13	3	16
Maria	6	10	16
Amy	8	1	9
David	8	1	9
Sue (worker)	20	0	20
Fen (student)	24	1	25

Before the second session started, Sue disclosed that Rose, Sheila and Maria had been users of the city centre day centre that had closed down very recently, and were unhappy about this closure. This was an important context for our PR group, as it influenced both discussion and subsequent action.

Content of sessions

Four sessions took place during the second and third phase of the project. The first session with this 'core' group of co-researchers included discussion of 'ground rules' for working together and ethical issues such as consent, and then started to explore co-researchers' perceptions of problems they had faced and continued to experience as people using mental health services. At the second group session, co-researchers continued to share their experiences of problems with services, and of discrimination. At the third session, I attempted to move the research on to problem-posing, to explore the broader socio-political context of their experiences and reasons why problems occurred.

The fourth session was a review session involving the project worker and co-researchers, which aimed to explore participants' views on the PR process to date. This session was planned as I was unable to attend, and I felt that my absence would allow co-researchers to be critical without becoming anxious about 'offending' me. I provided Sue with a list of prompt questions to use in this session (Appendix 10)[135], and asked her to make notes of people's replies for me.

Co-researchers discussed a wide range of issues at these four sessions, many of which reflected themes identified in the literature reviewed in Chapters Two and Four, including: experiences of inpatient psychiatric 'care'; experiences of physical treatments, including ECT; negative experiences of primary health care and social care professionals; problems with housing, benefits and transport; public misperceptions and stereotypes of mental health service users; loneliness and isolation; the effects of feelings of depression; and limited rights.

The following sections present details of co-researchers' views and comments on these issues, analysed in the context of theoretical and empirical literature on oppression and power discussed earlier in this dissertation.

---

[135] These review questions encompassed issues such as: the purpose of the group; how comfortable co-researchers had felt with issues raised; the structure of the sessions; the way information was being produced; the roles of the research student and the project worker; the desired timescale for the group; and views on whether the group should be closed or open to other service users.

Experiences of oppression and power relations

Experiences of the local psychiatric hospital

Discussions took place throughout these sessions on people's experiences as 'inpatients' at the local psychiatric hospital, in which they had all spent time. Echoing other empirical evidence (e.g. Goodwin et al, 1999; Rogers et al, 1993), four co-researchers recounted largely negative experiences of 'care' and support there, although Maria felt that her stays had been beneficial.

'Total institutions' and disciplinary power

Many characteristics of Goffman's (1961) 'total institution' (described on p.110) could be identified in co-researchers' comments. Issues raised included: lack of contact between staff and 'inpatients'; long periods of time spent sitting with nothing to do; lack of flexibility in arrangements for taking medication; and being made to go to bed even when sleep was not possible due to medication.

These latter comments regarding strict control of people's time, space and activity have also been identified by Foucault (1977) as characteristics of 'disciplinary institutions' (see p.57). A primary element of Foucault's disciplinary institutions is their use of surveillance and observation to control 'inmates'. Both Rose and Sheila talked about their unpleasant experiences of spending time in the observation ward, which they found oppressive and disempowering:

> You go in there to be supervised... you can't have a radio... or a television set. You just sit there all day doing nothing and two nurses... just sit there watching you. They won't speak to you. It's terrible... you're so intimidated by these two nurses... you feel all frightened. (Sheila)

Fear of violence

A key element of oppression has been identified as the fear or threat of violence (Young, 1990). Three female co-researchers commented on how frightened they felt during their stays in the psychiatric hospital:

> Rose I felt terribly frightened of everybody... You think they're going to harm you...
>
> Sheila ...I used to sleep downstairs on the settee 'cos I was too frightened to go to bed.

Amy highlighted her fear of other 'inpatients' and its negative impact on her mental health:

> People that are really causing problems... come over on some of the wards, and they're scrounging cigarettes and they hassle you... And the staff don't tend to do anything about it... it's supposed to be a place to relax and get yourself better but it's not at all, it's completely the opposite... (Amy)

These experiences reflect the finding of empirical work that women often experience harassment and abuse on mixed-sex wards (Payne, 1996).

Professional practice

Literature suggests that professional power operates strongly in relation to mental health service users, at individual and structural levels (see p.68-71), particularly if people are subject to sectioning under the Mental Health Act 1983 (Lindow, 1995).

Oppression at an individual level (Keating, 1997) was apparent in co-researchers' descriptions of negative interactions with hospital staff, including a lack of support and understanding, the use of patronising, hurtful and offensive comments, the expression of negative attitudes towards their behaviour, and the use of oppressive procedures such as observation and forced physical treatment. In this context, direct exercise of professional 'power over' service users was very apparent (Wilding, 1982). The following quotations are illustrative of co-researchers' comments on hospital staff:

> Rose Some of the staff are horrible.
>
> Amy Awful, yeah.
>
> Rose I mean, they shouldn't be in that job. You need somebody who's understanding and considerate.
>
> Amy I found that when I went in, I was put on (ward name), and... a lot of the staff weren't very helpful, and some of them were walking round with this chip on their shoulder... I was shut out with no shoes on at one point, in the pouring rain by a lady... and just left! I just felt abandoned.

Complaints included the lack of support for service users from staff, and their lack of consideration of the way service users might be feeling:

Mike ...you try talking to them and it's just 'Oh go and have a walk round the grounds'!

Amy Or go for dance therapy or something, you know, and sometimes if you were on medication and you were very tired, you couldn't do that... and if you couldn't join in them, they would just cut you off... it's all 'Pull your socks up'... and just left.

Nurses' reluctance to spend time with service users has been identified as disempowering in several empirical studies (e.g. Campbell and Lindow, 1997). Both Rose and Sheila felt that the nurses did not spend enough time talking to service users, as illustrated in this exchange:

Sheila The staff lock themselves in the office... and no-one's looking after the patients.

Rose They're not on the ward at all, only at dinner times, are they?

Sheila Only when they're giving you your medication.

Co-researchers clearly recalled upsetting comments made by hospital staff:

Rose ...the doctor said to me... if I couldn't look after myself he (her son)'d have to go into care and I'd have to go into sheltered accommodation... I thought that was a really bad thing and hurtful to say when you're going through a really bad time in your life.

Amy It's a bit like one of the nurses said to me 'You're acting like a child' and that hurt!

Rose You're under a lot of pressure.

Amy Exactly! I was in a state...

The doctor's threat to take away Rose's child was an extreme manifestation of his legally-mandated professional 'power over' service users (Wilding, 1982), and the social control function of his role was clear in his attempt to coerce her into 'normal' behaviour, i.e. to 'look after herself' according to socially defined norms. The infantilisation of service users by psychiatric hospital staff highlighted by Amy was also identified by participants in Goodwin et al's (1999) user survey (see p.114).

When I asked the group whether they felt they had been discriminated against by people because they used mental health services, Sheila immediately mentioned the treatment she had received from psychiatric hospital staff:

> I felt really badly treated by (psychiatric hospital), the psychiatrists... I felt... I'd been treated like dirt, pushed around and not allowed to know what they were saying about me. (Sheila)

Lack of opportunities for user involvement

I asked co-researchers whether they felt there were any opportunities at the psychiatric hospital to voice their opinions or concerns about their treatment, for example via the Patients' Council there. None of them recalled having received information about this or to having had any involvement with it. Sheila mentioned the weekly ward meeting with doctors, but stated that she was "always too frightened to say anything... I think if you did, you'd be just told to shut up". Similarly, Amy felt that she would not have wanted to approach staff to talk about her difficulties, as "they were quite abrupt, a lot of them, and you felt like you couldn't trust them".

Unsupportive staff attitudes, together with a strong perceived power imbalance between professionals and service users in this context, clearly combined to limit opportunities for co-researchers to have a say in their treatment. This fear of the staff was likely to have been exacerbated by their considerable power over service users in an inpatient context (as discussed on p.108-114).

Psychiatric hospital's negative impact on health

Co-researchers felt that their experiences in the psychiatric hospital had impacted negatively on both their mental and physical health. The hospital was clearly not seen by most as a place which aided recovery: indeed, three co-researchers commented that their symptoms of distress were as bad or even worse after spending time in the hospital. Both Rose and Sheila stated that they would prefer to be at home if they were feeling unwell:

> Rose I don't never want to go back in there anyway. I'd rather stay at home if I was ill.
>
> Sheila I always feel when I go down to (psychiatric hospital) that I'm too ill to be in hospital... I'd rather be at home.
>
> Rose At least if I didn't feel well I could go and have a sleep or do my own thing.

Both co-researchers were therefore expressing a preference to self-manage their symptoms of distress, rather than receive what they perceived as unhelpful and damaging professional 'care'. This finding reinforces Foucault's (1977) arguments in relation to disciplinary power operating both within psychiatric hospitals, viewed as punitive rather than supportive and healing environments, and more widely via the

carceral society's "generalized surveillance" (p.209), which might cause service users to monitor and disguise their behaviour.

With regard to physical health, Maria talked about her unhappiness at the weight she had gained during her stay in the local psychiatric hospital (possibly as a result both of the lack of activity and of side-effects of medication), and its impact on her ability to be independent:

> The time I've been into (psychiatric hospital), I've put weight on. I can't walk now, I'm very tired... I can't go to the shop, I can't look after myself properly... I'm by myself and I worry a little bit... (Maria)

However, it should also be noted that Maria made positive comments about care in the psychiatric hospital, stating "the last time I was there, the doctors and nurses helped me loads". Similarly, Mike repeatedly expressed a desire to be readmitted to this hospital, despite his comments about the lack of activities there and the negative attitudes of staff. This desire seemed to be linked to feelings of depression, loneliness and fear for Mike.

Experiences of physical treatments

Another major theme identified by co-researchers was experiences of physical treatments, including psychotropic medication and electro-convulsive therapy (ECT). Co-researchers felt that medication was used by professionals as an 'easy option'. Amy commented that "it's all popping pills and not enough support", while Sheila felt that the professional response was "when you're in trouble... 'Take all your tranquillisers!'". Co-researchers identified an over-reliance by doctors on medication as a 'solution' to their mental distress, and a lack of information on side-effects of medication:

> If you go to the doctor with depression, they do nothing about it... They just sort of sit there and go goggy-eyed,... give you a prescription and shove you out of the door. (Mike)

> I've found if your medication doesn't work, they're writing out a prescription before you've finished talking... he'll... say something along the lines of 'Well, short of anaesthetising you, there's not really a lot I can do', so you think 'Well where do I go now?' (Amy)

Such criticisms reflect other empirical evidence from service users of doctors focusing on diagnosis and treatment rather than attempting to understand the cause of people's distress (as discussed on p.113-114), as a result of the success of the biomedical approach to 'mental illness' in establishing prevailing 'discourses of truth' (Foucault, 1980, explored on p.56).

Amy described how she had decided to stop taking her medication due to serious side-effects (as highlighted on p.111). Amy felt that there was a lack of alternative support for people who did not wish to take medication (see p.17):

> ...now when you're off the medication, there's no facilities there to help with that. So there are plenty of people to help with the medication, but when you don't want the medication, you've still got this problem... you need the help. (Amy)

Maria raised the issue of ECT during a discussion about feelings of depression, stating that she had received a lot of ECT and that it had worked very well for her. She asked Rose whether she had also experienced ECT, which Rose said she had received involuntarily and had found very unhelpful:

Rose	...I had to have it because three or four doctors put me on a section, so I didn't have no choice, I had to have it...
Maria	It helped me lots to get well.
Rose	I felt just as ill when I came out as when I went in. When I came out I felt alien... My surroundings, I didn't feel as if I was part of it... I felt as if I was far away, on another planet.

Rose's side-effects of feeling 'cut off' and 'not yourself' have been related by other service users as a result of ECT (Arscott, 1999; Beeforth et al, 1990), powerfully highlighting the serious consequences for mental health service users of compulsory treatment. Such violation of people's basic human rights is clearly oppressive, and represents an extreme expression of professional 'power over' people (Wilding, 1982).

Contact with other health and social care professionals

Beyond inpatient services, co-researchers recalled oppressive experiences of contacts with community health and social care professionals. General practitioners (GPs) were a primary target of criticism by co-researchers. While Sheila commented that her current GP was very good, her interactions with previous GPs had often been oppressive and dehumanising. She recounted the way in which one GP had removed her from the practice list due to her use of the emergency GP service for panic attacks, and another had made hurtful comments:

> My husband was once told that I was committing a crime - I went out on the street naked once, I was really upset, and the psychiatrist come and said that he should phone the police... And other times the doctors have said 'Oh, she's just very inadequate', things like that, so I really felt quite put down by them, to be honest. (Sheila)

Other co-researchers felt that GPs did not show adequate understanding of or interest in mental distress, particularly feelings of depression. Criticisms included their lack of time to talk to patients during appointments and the lack of continuity in seeing the same GP each time. Co-researchers' comments suggested that while they did use their GP when feeling unwell, these encounters were often unsatisfactory and at times disempowering. The way in which 'street-level bureaucrats' (Lipsky, 1980) such as GPs exercise professional power and control service users via the setting, content and timing of their interactions with service users (see p.65) is clear in co-researchers' complaints.

Amy highlighted the problem of community mental health staff not attending appointments, and their lack of respect in not always informing service users:

> I used to have care plan meetings every three months... One was cancelled and I wasn't told... if anything's been postponed, they don't phone... and if you've got a taxi up here and they've pulled off, you're left stranded... You've kind of built up your hopes to see somebody and then they're not there. (Amy)

This lack of consideration towards service users is another element of professional power, highlighting the way in which professionals can operate services for their convenience rather than for that of service users (as discussed on p.65-66). The

event recounted by Amy above involves practice which clearly runs counter to professionals' professed adherence to 'user-centred' ways of working.

Amy raised her need for someone to talk to about issues when she was at home, which Rose also emphasised:

> … sometimes day care support is not quite enough. 'Cos when you go home and you've got this endless loop in your mind, it doesn't matter how many tablets you take… it's not going to help it, but talking to somebody who knows a bit about it and coming to you if you can't get about so much (would help)… (Amy)

Sheila expressed great anxiety that her community care worker, whom she found very supportive, would 'drop' her at some stage in the future and she would lose that support. Rose recounted her experience of being 'dropped' by the CPN that was visiting her:

> I had one, but she said 'Oh, you're doing fine', she said, 'you don't need a nurse any more'… She said 'We've got a lot of patients that are very sick and need us'. (Rose)

This experience reinforces Wilding's (1982) argument that professional definitions of need tend to be imposed upon people rather than agreed, thereby disregarding and devaluing individuals' own understandings of their situation and needs (as discussed on p.63-64).

Both Sheila and Maria commented on how happy they were with the service they received from their community care workers, and how much these workers helped them. It is interesting to note that the professional input that co-researchers appeared to find most valuable was that involving practical support and having someone to talk to, rather than any form of medical intervention (see p.112).

Rose and Mike felt that the lack of adequate support from community professionals was due to insufficient resourcing of community services to replace inpatient provision:

> They shouldn't have closed all these hospitals down and put people in the community... if they haven't got the backup when they come out. That is unfair, that's really bad... they're saying there are people there to look after them, but there isn't. (Rose)

Here, Rose was demonstrating her awareness of a socio-political context to her experiences of inadequate support and discrimination, in terms of government policy and resource allocation.

Lack of information on service user rights

Co-researchers did not recall having been provided with information about their rights as mental health service users. For example, none were aware of their rights to care plan reviews or to have a keyworker whom they could see regularly. Mike commented:

> Nobody really knows their rights, do they? You don't know what you're entitled to and what you aren't entitled to. Nobody tells you... (Mike)

A lack of information has been highlighted as a way of restricting people's power (Read and Wallcraft, 1992), and the corresponding denial of rights can be identified as an element of oppression (see p.40).

In addition to experiences with health and social care professionals, co-researchers also discussed issues in other aspects of their daily lives, including housing, transport and welfare benefits.

Housing

Both Amy and Sheila expressed unhappiness with their housing situation. Amy noted that she was attempting to be rehoused by the local authority, as her accommodation was aggravating her mental distress "because it's so small and everything's on top of you". Amy's comment illustrates the way in which material conditions are likely to have a negative impact upon mental health (Sayce, 2001a).

Amy did not feel that the council's housing system was sympathetic or understanding towards her mental health needs. She also found the bureaucratic process very

unhelpful for service users, as the housing office took a long time to assess people's cases and did not inform service users of progress being made.

Transport

Transport was an important issue in co-researchers' lives, as most did not own cars and therefore relied upon public transport, taxis or lifts from other people to be able to live independently. Sheila reported difficulties in travelling to the host organisation, which meant that she could not attend as many drop-in sessions as she would have liked. She had problems in using buses, and could not afford taxis on a regular basis. Rose, who also lived some distance from the host organisation centre, experienced similar difficulties with transport, compounded by her mobility problems which restricted her ability to walk to bus stops.

Rose and Sheila mentioned a council-subsidised transport scheme that was available for them to access, but noted that the scheme was often unable to 'fit them in' or to pick them up at the right time. This meant that co-researchers either had to miss a drop-in session altogether, or leave the session hours before it had finished. Both Rose and Sheila were keen to express appreciation for the service's efforts to accommodate them, but the service's limitations clearly had an impact on their ability to access the host organisation's services. Rose also noted that she spent all of her mobility allowance on taxis to enable her to attend valued services.

Benefits

When I asked co-researchers whether they felt they were receiving the benefits to which they were entitled, Sheila noted that she was attempting to obtain a higher rate of disability living allowance to enable her to afford taxis more often:

> I get my disability living allowance once a month but that's £26, and my husband and my joint income is less than £100 a week, so we haven't got much money to spare for taxis and stuff. (Sheila)

In general, the group felt that they knew where to go to obtain advice and support on benefits (including the Citizens Advice Bureau, and social workers). Nonetheless, co-researchers' dependence upon benefits was likely to result in difficult material

conditions, which research has found to have a significant impact on peoples' mental health (Davis and Bird, 2001; Sayce, 2001a), and to restrict their access to opportunities for meaningful activities and appropriate services (Oliver, 1996).

Public misperceptions of mental health service users

In relation to discrimination, I asked co-researchers whether they thought other people knew that they used mental health services, to which they all replied no. They were clearly wary of people's prejudices about mental distress, as this exchange illustrates:

Amy	I suppose everyone's got their opinions, but then sometimes when stuff hurts, it's not wise to speak your mind...
Sheila	Yeah, and I had care orders put on my children because I was a mental health patient. Social workers were always coming round and everything, taking my children into care...
Fen	But in terms of where you live and your neighbours and stuff, that's OK?
Amy	I keep myself to myself, so I'm OK.
Mike	Me too.
Sheila	We don't have much to do with our neighbours...
Rose	I never told anybody... They didn't know who the people were that came to see me. I talked to my neighbours but I didn't discuss my business.

This self-imposed isolation and segregation from neighbours can be interpreted as a serious social impact of oppression experienced by mental health service users, with fears of negative reactions contributing to an ongoing relationship between discrimination and social exclusion (Barnes and Shardlow, 1997; Sayce, 2001a). Such fear of being monitored and subsequent self-monitoring of behaviour (as discussed on p.58) clearly has oppressive consequences for people with experience of mental distress, limiting their ability to function as active citizens in society.

Sheila's comment about social workers taking her children into care is another example of extreme and legally mandated professional 'power over' people (Harris, 1997), which she felt was a direct result of her status as a mental health service user.

I asked co-researchers whether it was difficult not being able to talk to people about these issues, but they all felt that it avoided problems associated with people's fears and misconceptions:

> Rose …because they don't understand, they haven't gone through it themselves. People are frightened of you, they think you're mental.
>
> Amy They think you're a bit loopy or something… People read things and don't really know.

This socio-cultural dimension of oppression (Keating, 1997) experienced by co-researchers was further evidenced in their accounts of a local attempt to open a service for mental health service users, which had been defeated by a petition from mothers using the nursery next door to the proposed site. This event echoes other accounts of proposals for community mental health facilities being thwarted by protests from residents (Repper and Brooker, 1996), as discussed on p.120.

Co-researchers were upset by the implication that people who used mental health services were dangerous (as highlighted on p.121), and felt that this view was due to ignorance and stigma. This discourse of 'dangerousness', perpetuated by the media and general public, can be seen to operate ideologically to sustain oppression (see p.121). In this way, the close relationship between discourses and power relations (Foucault, 1998) can be seen to have a significant and negative effect on mental health service users.

Loneliness and isolation

One of the main issues raised by co-researchers was their sense of loneliness and isolation both during the day and in the evenings, a clear aspect of the social and psychological impact of oppression (see p.122-123).

Sheila talked about her unhappiness at the closure of the social services day centre, which she used to attend five days a week, viewing the host organisation's level of drop-in provision as inadequate in comparison. She felt that the lack of day care provision was having a significant negative impact on her mental health:

> I get really depressed now. This is my third week at home. I'm in on a Saturday taking tranquillisers, you know, getting ready for bed before 5 o'clock. (Sheila)

Such dependency on mental health services, fostered by years of contact with the mental health 'system' and corresponding segregation from mainstream facilities, can be seen both as an element of institutionalisation, and also as a result of cultural acceptance of professional intervention (see p.67).

All co-researchers felt that they did not have enough to do during the day. It became clear from their comments that having organised daytime activities to attend was an important factor in alleviating feelings of depression and loneliness:

> ...being at home's no good for you if you're depressed, you have to get out of the situation. You need somebody to talk to about it, you need something to occupy your mind. (Rose)

The strong need to have other people to talk to expressed by co-researchers echoes the self-management literature (see p.94-95), which emphasises talking about problems and maintaining contact with other people as important strategies to maintain good mental health (Allott and Loganathan, 2002; Curtis, 1997; Martyn, 2002). Indeed, Rose felt that not having enough to do and being isolated could lead to her becoming unwell and being readmitted to inpatient facilities.

Amy commented on the related issue of what she called "talk groups", and felt that there was a lack of local support groups "where I can talk about the nervous problems I have... you can get out and meet other people, and then you realise that you're not the only one with the problem". The benefits of talking to other people with similar experiences expressed by Amy are reinforced by other empirical evidence on user groups and self-help groups (see p.128-129).

All co-researchers also experienced feelings of loneliness and isolation in the evenings, compounded for the three who lived on their own (Maria, Mike and Rose). This loneliness is illustrated in the following exchange:

Rose I feel lonely at night time. I'm on my own from when I go home.

Maria I get lonely. I go to bed early.

Rose I just smoke and smoke, 'cos I don't know what else to do.

Sheila I go to bed at 5 o'clock sometimes.

Maria We're sad! It's terrible! I lie in bed... nobody comes to see me...

Rose It's very lonely. I'm a person who needs to be with people. I don't like my own company. I can't stand my own company. It's terrible, isn't it?

Mike made his first comments on this issue at the third group session, concurring that "I get a bit sort of lonely and a bit depressed in the evenings".

Elements of internalised oppression (Freire, 1972) can be identified in these comments. Negative self-perceptions were apparent, as was a limited outlook on life. Co-researchers identified a lack of purpose in their lives: Sheila stated that she would stay in bed all day if she did not have the day centre to attend, and three co-researchers noted that they often went to bed very early. This loneliness and isolation was a recurrent theme throughout our project.

Experiences of mental distress

A long discussion took place at the third session about the effects of depression, instigated by Rose and in which all co-researchers took part:

Rose It's dreadful. It's like going through a dark tunnel, isn't it, when you're not well... you don't know when the depression's going to lift from you... You're just waiting for the time when you come out of it... Does anybody else feel like that?

Mike Yes, as you say it can be a few weeks or a few months, can't it...

Sheila Or years...

Rose I think as I'm getting older I'm learning to cope with it more. When I was younger I was in hospital for a year at a time. It's the hardest part, being in hospital, you know. I used to get that choking in my throat when I had to go in hospital...

Maria It's terrible being ill all the time.

Rose It's ruined my life, you know, because I've never really lived...

This was a powerful sharing of experiences, which led to Maria taking the initiative and asking questions of other co-researchers for the first time. She asked Rose how old she was when she first started feeling unwell, and Rose, Sheila and Maria all identified having first experienced mental distress around the age of 18 or 19. Maria commented that "I was stronger... now I feel more pain, I feel older, tired and ill".

Co-researchers' experiences with and concerns about their mental distress pervaded our work. They talked at length about the effects of their distress on their quality of life and on that of their families. It is therefore important to acknowledge the impact of feelings of distress on mental health service users' lives, even though these feelings are linked to and exacerbated by people's experiences of oppression and disempowerment.

Indeed, the above exchange illustrates that despite years of contact with mental health services, co-researchers' experiences of depression did not appear to have been alleviated by professional 'input'. Rose stated that she had learned to cope better with these experiences, suggesting an increasing self-management approach (see p.94) in the face of ineffective medical intervention. This finding reinforces the argument (summarised on p.35) that the medical model of 'mental illness', with its corresponding diagnostic and treatment systems, is an inappropriate way of understanding distress, and one which has considerable negative consequences for people 'diagnosed' as in need of psychiatric 'intervention' (Johnstone, 2000; Lindow, 1995; Rogers and Pilgrim, 2003).

Use of medical model as explanatory framework

However, despite co-researchers' negative experiences of medical practitioners, acceptance of a medical conceptualisation of that distress seemed relatively strong in the group. All of the co-researchers identified themselves as 'ill', with Rose often using the analogy of physical illness to talk about her mental distress:

> For mental hospitals, they only give half of what they give to a general hospital... it's not right, is it? ...we should have the same money, 'cos people are sick in the mind just like the body... (Rose)

Although co-researchers challenged the use of medication and hospitalisation as 'solutions' to their distress, it appeared that they were still looking to professionals to provide *better* support rather than looking beyond statutory services, for example to other service users. This cultural acceptance of professional 'intervention' for their distress may have arisen in part due to the considerable length of time for which most co-researchers had been labelled as 'mentally ill', and the resulting 'internalised oppression' (highlighted on p.44). This finding gives support to Lukes' (1974) suggestion that power can be exercised by subconsciously shaping and manipulating people's views, and to Foucault's (1980) argument about scientific knowledge's success in producing 'regimes' or discourses of 'truth' (as discussed on p.55).

The 'self-fulfilling' nature of labels of 'mental illness' (highlighted on p.20-21) could also be seen to have some resonance with these findings. Most co-researchers tended to have had 'careers' as 'mental patients', with years of ongoing contact with inpatient and outpatient mental health services, and social interaction often limited to interaction with other service users, for example at the drop-in centre.

Exploring reasons behind negative experiences

At the third session, I attempted to move the group on to Phase Three of PR, namely to think about the reasons why some of the problems they had been discussing arose, to make links with the broader social and political contexts.

Rose immediately referred to her experience with the CPN who told her that she no longer had time to visit her as other service users took priority. Rose and Mike both felt that community mental health professionals had too many service users on their caseloads. They felt this also applied to GPs, who Mike said were "very abrupt... you try and explain to them, but they haven't got time for that".

When I asked co-researchers whether they felt lack of time was the only reason why some GPs were experienced as unhelpful, Rose stated that she felt it was also due to a lack of interest on GPs' part, and a lack of understanding of depression. Sheila repeated her experiences of being removed from GPs' lists because "they thought I was too much trouble".

In relation to psychiatric hospital staff, all three co-researchers present felt that they did not care about service users, as shown in this exchange:

> Rose They're not a bit understanding... I don't know why they are nurses, they're really horrible to the patients...
>
> Fen So it's about their attitudes...?
>
> Rose Yeah. I thought it was a vocation, but it doesn't seem to be...
>
> Sheila They don't care... you were treated like you were worthless...
>
> Rose You're so much trouble, aren't you, in the hospital.

These attitudinal issues highlighted by co-researchers can be related to issues of power and oppression explored in earlier chapters. Health professionals are trained in a particular, biomedical body of knowledge and way of conceptualising issues (Wilding, 1982), which can be seen to lead to a view of mental health service users as 'other' and on some occasions as 'inferior' (Dominelli, 2002). Structural constraints on professionals' roles, for example the lack of adequate funding which forces them to make evaluative decisions about resource allocation (Adler and Asquith, 1993; Lipsky, 1980), also provide an oppressive socio-political context for the negative consequences of such decisions for mental health service users.

In addition to this powerful evidence on the nature of oppression and power experienced by co-researchers, their comments and actions can also be examined to consider empowerment processes and power dynamics operating within PR.

Processes of empowerment and power relations in PR

Operational definitions of individual and group empowerment highlighted in Chapter Six (p.201) are used in this section to frame my analysis of empowerment processes occurring during our PR project. The following section will also include analysis of participation and power dynamics occurring within the group, as these are closely linked to empowerment processes.

Individual participation and empowerment processes

At the start of the project, it was important to establish the extent to which elements of individual empowerment were already evident amongst co-researchers. To achieve this in a sensitive, unobtrusive and non-alienating way, I made detailed observation notes on each co-researcher and recorded their comments on both their experiences and their views of the group process. The following analysis is based on these data.

With regard to people's existing sense of personal power, control, confidence and self-esteem, it was apparent that this varied amongst co-researchers. Co-researchers' confidence was partly reflected in their participation in discussions. At initial sessions, Rose and Amy contributed most, both initiating and developing discussion and asking questions of other co-researchers. Sheila and Mike were quiet and more prompting was required to encourage them to participate, although they gradually became more comfortable and contributed more as sessions progressed.

Maria only participated unprompted on occasions, and tended to engage and disengage throughout sessions. Her participation appeared to be limited to some extent by her language difficulties, as well as by leaving sessions midway to get her taxi. However, by the third session, Maria was contributing more unprompted than she had before, and added comments about her experiences to issues discussed in previous sessions. At one point, Maria questioned Rose about her experiences of mental distress, which she had not done in previous sessions. Maria's greater involvement in this session made me feel more confident that she did understand discussions and could participate if she chose to do so.

Levels of 'self-esteem' amongst co-researchers could partly be detected in comments about their experiences and aspects of daily living[136]. For example, Maria's comments about her weight issues and loneliness, Rose's assertions that she disliked her own company and needed to be with other people, and Sheila's revelations that she tended to go to bed early and self-medicate with tranquillisers all revealed a

certain level of anxiety and lack of positive self-concept. Assertion of personal power by co-researchers was limited at this stage, with the exception of Amy. She appeared to be the most confident of the group and was using her personal power to obtain services and improve her situation[137]. Her level of self-direction and confidence in managing her distress and asserting rights was not evident amongst other co-researchers at this point.

With regard to positive self-definitions, comments made by co-researchers about being "sad" (Maria), "depressed" (Mike), lacking in purpose in their lives (Sheila), and depression having "ruined my life" (Rose) suggested that most co-researchers' self-definitions in these early stages could have been more positive (although it was also clear that they exhibited considerable resilience and strength in the face of oppressive and disempowering events experienced over the years).

Dependency on professionals and statutory services was also evident in many of the co-researchers' comments (illustrated on p.227), and contributed to my sense that most co-researchers had a relatively limited sense of personal power and control in relation to managing their symptoms of distress and living their everyday lives.

Obtaining desired information is identified in the literature as an aspect of individual empowerment processes (see p.90). Even in these early stages of our PR project, it was clear that co-researchers were obtaining valuable information both from one another, for example about changing GPs and cutting down medication, and from the project worker[138].

Another element of individual empowerment that appeared to be operating for some co-researchers was validation of their experiences both via being in a space which felt safe enough to be honest without fear of sanctions, and via recognising their

---

[136] Collins English Dictionary (1986) defines self-esteem as 'respect for or a favourable opinion of oneself'. However, it is acknowledged that self-esteem is a complex concept, which can be seen to incorporate many of the intra-psychic components highlighted by Fitzsimons and Fuller (Table 1, p.87).

[137] Examples included making decisions to find alternatives to taking medication, fighting for her rights to be rehoused, accessing the Citizens Advice Bureau for support, and making lists of questions to take with her when she went to see her GP.

commonality with others' experiences. Co-researchers seemed to appreciate having the space to share their problems and experiences. For example, Rose commented that "you know you can talk about what you really feel".

With regard to asserting personal needs, another identified element of individual empowerment, some of the co-researchers were already beginning to see the PR group as a potential avenue for achieving this, as witnessed in Rose's comments about engaging in the research and action phases of PR:

> I just hope that somebody will take notice of it and things will alter... Let's shake them up!... Go out to doctors and things, (the psychiatric hospital), and shake them up. (Rose)

Sheila was also clearly interested in this aspect of the work, although she was less confident, describing the group as "a voice in the wilderness".

Group empowerment processes

As highlighted above, group empowerment processes include processes of collective consciousness-raising via sharing experiences. In these early phases of PR, it was evident that such sharing was occurring and was perceived as valuable by co-researchers. Indeed, there was positive interaction between co-researchers from the very start, as they shared experiences, questioned one other and discussed their problems. Amy noted the commonality of experience between co-researchers, commenting "it's surprising that we've experienced the same type of things, like with hospital and GPs", while Sheila mentioned liking to "see if other people feel the same as you".

Mutual support also began to emerge between co-researchers. For example, Rose commented that she had changed GPs and was extremely unhappy with her new GP, and other co-researchers helpfully explained to her that she was entitled to swap doctors. On another occasion, Amy was talking about stopping taking her medication and another co-researcher gave her advice on how to cut down slowly to minimise withdrawal symptoms.

---

[138] For example, when asked to do so, Sue provided co-researchers with information on arrangements for care plan reviews, support available to people when they felt they were becoming unwell to avoid hospital

Co-researchers seemed pleased when I explained to them that we could use the information emerging to take action. They were starting to understand that they had the power to act on some of these issues, moving towards the element of participation in joint action also identified as a group empowerment process. Their comments on this included:

> Rose I think (we) should let them know what people think and experience.
>
> Amy At least if other people go in, it might help them as well. So if things do get better in hospitals, at least people can be treated better.

Operation of power dynamics in PR project

In recognition of Foucault's (1998) assertion that power relations are present in all social interactions, power dynamics operating between the different parties involved in the project are explored below.

Between co-researchers

There did not appear to be a clear 'leader' emerging within the group, although Rose was facilitative of other co-researchers[139]. Rose, Amy and Sheila tended to dominate discussions, with Mike and Maria contributing less frequently. However, opportunities were provided for all co-researchers to participate, and co-researchers were respectful in allowing one another to speak and in not interrupting.

Between the research student and co-researchers

With regard to power dynamics between myself and the co-researchers, I found that I had to take quite a directive role in the initial stages of some sessions, as co-researchers were not always very forthcoming in my open requests to them to choose what they would like to talk about. At times I felt that co-researchers were looking to me as the 'expert' or 'professional' facilitating the group and were therefore expecting to be told what to do. This may partly be due to my attempts to structure the sessions to some extent to move the group through the PR process, and also to

---

readmission, and services and support that the host organisation could provide.

[139] For example, when Mike talked about wanting to be readmitted to hospital as he did not feel well, Rose was supportive in asking him to explain how he was feeling and in emphasising the need to ask his psychiatrist to give him reasons for not readmitting him.

the fact that all group members were learning how to 'position' themselves in the group. However, once discussions were underway, co-researchers were usually happy to determine their direction and my intervention was not necessary.

Co-researchers also felt confident enough to ask me for clarification about my role and the purpose of my research. At the end of the third session, for example, Sheila asked me what I was studying for. When I explained that this was a study for my research degree, she sought clarification that they were "not just part of your study". Similarly, another co-researcher asked what we would be doing with the information from the project, namely whether it was just for my research or whether it would "go to somebody who'll do something about it". These exchanges were extremely positive in showing both that co-researchers were happy to challenge me for justification of the value of this research, and that they were keen to see action taking place as a result of PR.

Between the project worker and co-researchers

As a representative of the 'host organisation', and therefore a service provider, it might be expected that there would be clear power imbalances in interactions between the co-researchers and project worker. However, evidence from these early sessions did not appear to support this position. Although it is possible that Sue's presence influenced co-researchers' behaviour, they nonetheless appeared happy to criticise the host organisation's service provision in her presence[140]. Furthermore, co-researchers seemed to have a positive and comfortable relationship with Sue, and to view her as an ally and source of support rather than as a 'professional' to whom they were 'in opposition'.

Apart from providing information for co-researchers on services of which they were unaware, the project worker took a 'back seat' in these early sessions. At the third session, the project worker did start asking questions of the group in addition to my questions, yet these were relevant to the discussions and did not seem to be leading.

---

[140] Indeed, some co-researchers may have been waiting for the opportunity to criticise the drop-in centre's service provision, particularly in comparison with services provided by the recently closed and much valued social services day centre.

Sue appeared to view herself more as a member of the group than as a detached 'professional'.

After the initial sessions, Sue expressed concern about whether the host organisation would be identified in my dissertation, clearly anxious that the critical issues being raised by co-researchers might have repercussions for the host organisation and its relationships with professional groups and funders. While Sue did not attempt to suppress discussion in the group, this concern was nonetheless clearly an element of the power relations operating between the voluntary organisation and its funders.

Between the research student and the host organisation

At this early stage of the project, my relationship with the host organisation was largely positive. The new manager had been informed of the group and expressed support for its work. I also received valuable feedback from another host organisation worker, who stated that she felt the co-researchers were benefiting greatly from attending the sessions. While the host organisation was therefore informally monitoring the progress of our work, via feedback from Sue and the co-researchers, they were not attempting to influence it in any overt way that I could detect.

In addition to considering issues relating to oppression, power and empowerment, these fieldwork findings also shed light on methodological issues in PR.

PR methodological principles in practice

As outlined in Chapter Five, PR should comprise processes of social investigation, education and action. Groups which have traditionally been research 'subjects' become active researchers, with a corresponding redistribution of power to give control of the research to the group involved and facilitate their participation in all stages of the research process. This implies a new role for the 'external' researcher, as an enabler and supporter rather than an 'expert', adopting a committed rather than 'neutral' approach and engaging in critical reflexivity. The next section examines the extent to which Phases One to Three of our PR project adhered to these

principles[141]. Our experiences are also compared with those of Maguire (1987) and her co-researchers, as this was the model upon which our PR project was based.

Processes of social investigation, education and action

Social investigation began during Phase Two as co-researchers explored their experiences to understand more about them. Indeed, PR's aims of facilitating the sharing of experiences and identification of common problems were occurring from the start of the project. Co-researchers stated that they felt safe to discuss their problems and experiences together and commented to Sue that they raised issues that they would normally be fearful of discussing, possibly due to their awareness of disciplinary power operating (as highlighted on p.230). This dialogue continued throughout these initial phases, encouraging people to return to themes, add to them and share more experiences in a way which they did not appear to have done before.

PR also aims to be an educational experience. Maguire's (1987) framework identifies Phase Three as a formal educational phase which links people's individual definitions of problems with the broader structural and social context. My attempt to move the group on to Phase Three was problematic, in that co-researchers were clearly not accustomed to thinking about their experiences in relation to the wider socio-political context and I was anxious about imposing such explanations on them. This echoed Maguire's (1987) finding with women in her PR project that:

> They made few linkages between their individual problems and structural causes of sexism, racism, or classism... Many women could not translate their direct personal experience into abstract theory. (p.146-147)

This was similar to the experience in our group in that while co-researchers were able to talk about health professionals' attitudes and resource constraints, and to a lesser extent public prejudice and stigma attached to labels of 'mental illness', they found it difficult to think in more abstract terms about the roots of some of the problems they had experienced.

---

[141] Power relations within the PR process have already been explored in the previous section and are not therefore discussed here.

In my initial plans, I had hoped to facilitate Phase Three by introducing theoretical concepts such as oppression and the social model of disability into group discussions. However, it quickly became evident that co-researchers did not view their worlds in this way. I felt that to attempt to introduce such theoretical frameworks into their discussions would be a problematic and potentially alienating activity, and that it was important to remain open to the way in which co-researchers wanted to define their experiences and relationship with the world.

Co-researchers did not therefore undergo an educational experience in the academic sense of learning about social theories. Nonetheless, the group was an educational experience for co-researchers in other ways. Co-researchers learned from one another, both in the form of new information about their situations and access to services, and in recognising commonalities of experience.

PR emphasises mutual learning, and was also a profoundly educational experience for me as a research student. I learned first-hand about co-researchers' experiences of living with mental distress and about issues that were important in their lives.

Participation at all stages of the research process

In Phase Two, co-researchers' involvement in establishing ground rules was quite limited (although we did revisit the ground rules informally as issues arose), possibly as they were not used to working in a group in this way and therefore setting ground rules was an unfamiliar concept to them. In an early session, I attempted to encourage the group to make decisions about its content and structure, but they appeared uncomfortable with this. Our experiences led me to believe that it might be unrealistic in PR to expect a group to want to take control from the start of the project. The confidence to take such control needed to be fostered in our group, and grew as people felt more comfortable. It therefore seemed appropriate for the researcher to play an enabling role in these initial phases.

Nonetheless, the group participated in discussions throughout Phases Two and Three, with 'problem-posing' engaged in by all co-researchers to varying degrees (as discussed in the previous section).

An important element of PR is to share knowledge creation with co-researchers (see p.167-168). To achieve this aim, I undertook every week to produce full transcripts of the previous session for co-researchers, inviting them to read them to check whether there was any content with which they were unhappy or upon which they wanted to elaborate. Co-researchers seemed pleased to see the extent of their discussions, and often read through these full transcripts during session breaks.

I was aware that the full transcripts might be too lengthy and inaccessible for some co-researchers to engage with. I therefore also produced sheets on which I had summarised main themes from the previous week's transcript (see Appendix 11), which we read through each week to use as a prompt for further discussion. After positive reaction from co-researchers to this approach to knowledge production, I decided to use this model throughout the project, producing both a full transcript and a summary sheet to maximise co-researchers' access to the information which they were producing. When co-researchers were not present at sessions, I attempted to include them by passing on all typed information from the previous session to them via Sue.

It was also valuable during these phases to build in a review of sessions to date, to enable co-researchers to take more control over the research process by making suggestions for changes to the process and for the group's future development. Co-researchers provided valuable feedback on the PR process during this review session (detailed in Appendix 11, p.454).

New role for 'external' researcher

I found my role in PR to be facilitator of a joint learning experience, enabling the group to make decisions rather than making decisions for them. However, it was sometimes difficult to obtain a balance between facilitating sessions and directing them, particularly in these initial sessions where co-researchers did not always seem comfortable in starting discussions unprompted and looked to me to pose specific questions. Maguire (1987) emphasises the importance of having dialogue in PR rather than merely using a standard interview format. Similarly, I used a structure to guide sessions but ensured that there was scope within that structure to encourage

dialogue. Once co-researchers got involved in discussions, I had to say very little as discussions flowed well. My primary role in these discussions then became to ask questions which developed points they were raising, to further explore issues.

Conclusion

This chapter has outlined my experience of working through Phases One, Two and Three of PR with a group of people using mental health services, analysed in the context of conceptual frameworks of oppression, power and empowerment.

Co-researchers highlighted a wide range of experiences of oppression and power relations as people using mental health services (see p.219), which both echoed themes from other research presented in Chapter Four and reinforced theoretical and conceptual ideas on oppression, power and empowerment highlighted in Chapters One to Three.

The interconnectedness of personal, socio-cultural and socio-political dimensions of oppression was clear in co-researchers' comments, for example with regard to the exercise of professional power, as was the 'internalised oppression' which tended to result from such experiences. Foucault's work on power, in particular his identification of the disciplinary power present both in institutions and more generally in 'carceral societies' (1977), and of links between knowledge, power relations and 'discourses of truth' (1980), were also very relevant to co-researchers' experiences. This latter point was clear in co-researchers' seeming acceptance of the biomedical model of 'mental illness' as an explanatory framework for their mental distress, despite little evidence that this way of conceptualising their experiences procured any benefits for them.

With regard to the operation of individual empowerment processes, most of the co-researchers at the start of the project (with the exception of Amy) appeared to have a relatively limited sense of personal power and control in relation to managing their symptoms of distress and living their everyday lives, and relatively negative self-definitions.

Nonetheless, in relation to information seeking as an empowering process, it was clear that co-researchers were obtaining valuable information both from one another and from Sue. Another element of individual empowerment operating for some co-researchers appeared to be validation of their own experiences via sharing them with others in similar situations. Individual empowerment processes could therefore be seen to be operating for co-researchers in these phases of the PR project. Furthermore, such sharing of experiences and associated collective consciousness-raising has been identified as a group empowerment process, as has the mutual support that was emerging between co-researchers.

Power dynamics were clearly operating amongst the group, with certain co-researchers dominating discussions while I took a relatively directive role in the initial stages of some discussions. Although the project worker's presence at group sessions was likely to have influenced co-researchers' behaviour, they nonetheless seemed comfortable to criticise the host organisation in her presence, demonstrating the complex nature of power relations between service users and professionals.

In terms of putting PR's methodological principles into practice, the aims of facilitating the sharing of experiences and identification of common problems via dialogue were occurring from the start. My attempts to initiate a formal educational phase were largely unsuccessful, partly as co-researchers seemed more comfortable talking about the nature of their problems and experiences than about the reasons behind them. An important finding in Phase Three for me was therefore to always attempt to use co-researchers' terms of reference rather than imposing upon them a theoretical framework for understanding these experiences.

Co-researchers participated in discussions to varying degrees, but all did so increasingly as they became more at ease. Co-researchers were less certain about taking control of the group process, looking to me to do this when I attempted to hand decisions to them. An important aspect of PR is to always hand decisions back to the group, although this was sometimes hard to do in practice. It is therefore concluded that the implementation of PR methodological principles such as shared

decision-making and co-researcher control is likely to be a gradual process, which develops over time as co-researchers become increasingly confident in their roles.

The following chapter presents similar critical analysis in relation to Phase Four of PR, namely "researching social reality and analyzing collected information" (Maguire, 1987:41).

Chapter Eight: Researching Reality and Analysing Data

Introduction

This chapter presents critical analysis of the group's work during Phase Four, which involves joint work by co-researchers to design a research process, carry out research and analyse resulting data (Maguire, 1987:41). Co-researchers chose to carry out group interviews with health and social care professionals, using a topic guide based upon their experiences and concerns. A relatively lengthy preparatory phase occurred, before three interviews were conducted over a two-month period.

Section A describes activities undertaken to prepare for the research, and critically analyses processes of participation and empowerment and power relations operating. Additional comments by co-researchers on disempowering and oppressive experiences of services are also presented, to supplement their earlier accounts.

In Section B, interview findings are summarised and critically interpreted using the theoretical and empirical literature reviewed earlier, and processes of empowerment and power relations occurring are analysed. The final section considers issues arising from application of PR methodological principles during Phase Four.

Section A: Preparing to research

Content of sessions

At Sessions 6 and 7, co-researchers discussed ways of obtaining more information on issues raised in Phases Two and Three. I highlighted advantages and disadvantages of different research methods, including individual and group interviews, and postal questionnaires. Co-researchers decided that they would like to conduct group interviews with health and social care professionals.

Sessions 8 to 12 then focused upon planning and preparing for these interviews. Co-researchers developed and finalised a topic guide with possible questions to ask professionals[142], made decisions about who to invite to interviews, how and when these would be conducted, and how many they should hold. They also discussed whether interviews should be open for all centre users to participate in.

I sent letters to professionals that co-researchers had identified as possible interviewees, and received positive responses from a community care team leader (CCTL) and CPN (for a 'front-line worker' interview), a health authority team manager and social services councillor (for a 'manager/policy-maker' interview), and a GP.

Co-researchers' attendance varied during these sessions (as highlighted in Appendix 9, p.448). However, at the twelfth session, the group gained a new member as Sheila invited her friend David to join, and other co-researchers agreed to this addition.

Processes of empowerment and power relations in PR

Interesting empowerment processes and power dynamics were operating amongst co-researchers during this preparatory phase.

Individual participation and empowerment processes

Similar patterns of participation in sessions continued from the previous phases. Co-researchers interacted well, and appeared to feel comfortable asking one another questions. Participation levels of individual co-researchers varied, with Rose continuing to contribute most at sessions. Although Amy was present for only two sessions in this phase, she was very enthusiastic about the group's work and made considerable input.

Mike also contributed far more than he had done previously, talking significantly more, making suggestions, encouraging Sheila, and asking questions of other co-researchers.

---

[142] Amy wanted to write a list of her own questions for professionals, which I encouraged.

He took an increasingly strong role in these sessions, demonstrating rising levels of confidence and a sense of personal power, and enhanced skills in supporting others.

Sheila expressed a relatively negative self-definition in the earlier sessions of this phase, appearing to lack confidence in asserting her personal power. For example, when I attempted to move the group on to consider what to do about some of the problems raised, Sheila stated that she could not understand the point of this phase. She was pessimistic about the possibility of accomplishing anything, stating "we're a very small group of people, we're unlikely to achieve much", in contrast to Rose's more positive view of potential action by the group.

When discussing ways to obtain more information from people and services, Rose and Mike expressed enthusiasm for talking to people face-to-face, but Sheila felt that she would be too nervous to do this and appeared concerned about challenging professionals:

Rose	Why are you frightened of them?
Sheila	Well I'd feel like I was cross-examining them.
Rose	...if it wasn't for people like us, they wouldn't have a job, would they?... You don't try, you don't get nothing...
Mike	If you don't stand up for yourself, nobody else will.

This exchange demonstrated the difference in co-researchers' sense of confidence and personal power at this stage, and hence the variable extent of individual empowerment processes occurring.

However, when Sheila raised her unhappiness at the social services day centre's closure and it was suggested that someone could be invited to discuss this, her earlier reticence at taking part in interviews disappeared and she began to talk about attending interviews to listen and support other co-researchers. This represented a positive shift in her previous attitude, and an increasing awareness of her ability to assert her personal needs

(an important element of individual empowerment processes). Sheila explicitly wanted to interview the social services committee chair as the person she perceived to have made the decision to close the day centre, demonstrating her desire to obtain reasons for this decision. By the twelfth session, Sheila was articulating clearly her desire to interview the social services committee chair, stating "I'll tell him off". This increasing confidence and sense of personal power was very notable in Sheila, and continued to grow throughout this phase (as discussed on p.270).

Maria also began to participate more in discussions, asking questions of other co-researchers and contributing more when prompted, particularly on her experiences of inpatient care. At sessions when only a few co-researchers were present, Maria took a far stronger role, contributing to decisions and discussions about the interviews.

Rose was very confident about taking part in interviews, stating "they might not agree with everything what we say, but... they can learn from us and we can learn from them". She also emphasised the importance of achieving change from this process:

> We could gain a lot out of it... that's what we've done it for... to see that things are done differently, are improved for the better of the patients, isn't it? (Rose)

Rose clearly viewed the interviews as a way both of obtaining desired information and of asserting her needs to improve circumstances, both of which have been identified as individual empowerment processes. In contrast, Maria commented that she hoped "somebody nice" would come and "give us help... for the patients", illustrating her ongoing acceptance of dependency upon professional support (Illich, 1977).

Group empowerment processes

One element of group empowerment processes has been identified as participation in joint action to achieve change. Rose and Mike began to engage in such a process during this phase, wanting to express their dissatisfaction with services and to make changes. Co-researchers were clear that they would be directing the interviews for their benefit

and to their agenda, with Rose commenting that "we're the ones that have done all the work... we're the ones that are going to ask questions".

Operation of power dynamics in PR project

Power dynamics were clearly operating between all those involved in the project during this phase.

Between co-researchers

Interesting power dynamics were operating between Rose and Sheila. When Rose was present, she tended to dominate discussions while Sheila was relatively withdrawn. However, at the seventh session, Sheila was far more forthcoming once Rose had left. While Rose and Sheila were good friends, there appeared to be an element of competition or power struggle between them, although Rose also used her power in a productive way at times with Sheila, as can be seen in the exchanges quoted above where she and Mike encouraged Sheila to be more assertive.

The issue of their former use of the central day centre also appeared to have a bearing on this power dynamic. I gained the impression that Sheila had asked David, another former user of that centre, to join the group to support her, as she felt that Rose was adapting to life without this day centre and was not supporting her in her complaints about its closure.

Interestingly, both Rose and Maria commented at different sessions that they would not wish to return to this day centre and were happier with the host organisation's provision. This illustrated the way in which Sheila's constant references to the 'halcyon days' of the closed day centre created certain tensions and power dynamics with those co-researchers whom she felt should share these sentiments and yet in reality did not do so.

Another issue concerning power relations amongst co-researchers was that some appeared to feel more at ease when the group was smaller. For example, both David and

Maria were quiet at larger group sessions and far more talkative in a smaller group, leading me to reflect that they found it difficult to participate in the bigger group.

Between research student and co-researchers

I tried hard in these sessions to place decision-making with co-researchers, constantly asking how they would like to proceed and pushing them to make decisions about what they wanted to do. I attempted to ensure that any issues arising were discussed by all co-researchers before decisions were taken. The focus upon sharing power was an important PR principle to which I attempted to adhere, although this was made more difficult by the group's lack of clarity about how they might move on to the research phase, which led me to give them ideas about this. However, as these sessions proceeded, co-researchers started to take more control over the research process and make decisions about group activities, further equalising power relations between us.

Nonetheless, co-researchers continued to look to me to undertake administrative tasks, such as drafting a letter to invite professionals to interviews. While this could be seen as continuing their dependency on others to undertake tasks for them, such decisions were also positive in that co-researchers were confident to assert their preferences with me and to 'use' my skills and resources for their benefits, as advocated in PR (Dockery, 2000).

Between project worker and co-researchers

Although Sue was absent from some of these sessions, when she was present she sometimes took quite a dominant role, leading co-researchers to focus upon issues which they had not identified. For example, when questions to ask professionals were being discussed, Sue took on an inappropriately leading role and made several suggestions that reflected her agenda rather than that of the co-researchers[143]. This input diverted time from co-researchers' suggestions, and did not give co-researchers space to think through

[143] These suggestions from Sue included: why voluntary organisations were expected to take on multiple roles by statutory organisations; a need for volunteer driver schemes; and concerns about the new Mental Health NHS Trust being set up in the area to provide mental health services.

issues for themselves. She also pushed co-researchers to talk to the centre users' meeting about the research to involve them in this process, which again related to her wider agenda rather than to any expressed desire by co-researchers.

I raised this issue with her in discussion outside sessions, highlighting the importance of co-researchers making decisions and deciding the group's direction, and the corresponding need for us to 'take a back seat'. I felt that it was important to encourage her to reflect upon the way in which she had been using her power derived from her position as a host organisation worker, although I remained unsure whether she had taken on board these comments.

Between research student and host organisation

It also became apparent during this phase that uneasy power dynamics were operating between myself and the host organisation manager, who reported to me in conversation that she did not fully understand the research or my role in the group and commented sceptically on the nature of the research. I felt that I needed to spend some time with the manager to give her information on the project and to alleviate any concerns she had to maximise her support of the group. I felt that her lack of knowledge and understanding about the research was contributing to her feelings of insecurity and scepticism, possibly feeling threatened by this user-led work (with external university involvement) as a potential challenge to her very recently established power base and control of the organisation.

I therefore arranged a meeting with the manager, which dissipated some of these earlier tensions between us. Once the manager had clearer information on the research and on my own agenda within it, she appeared to be less threatened and more supportive, recognising that I was working in the interests of the service users rather than of some external organisation, for their benefit. This contact facilitated more positive power relations between us, highlighting the need to ensure that 'key stakeholders' in such

situations feel fully informed both from the outset of the project and as the research progresses.

On my return to the centre after the summer, I noted that positive changes towards a more 'user-led' way of working had been introduced in the host organisation. Users' meetings were being held every week to involve service users in decisions about the centre and its work, and the organisation of rooms had been changed to make the centre more 'user-friendly'. One consequence of this reorganisation was that the space we had been using for our sessions was no longer available, forcing us to use a room in the nearby community mental health centre. This moved us away from the host organisation's physical space and helped to create a greater feeling of independence for the group, altering to some extent the power dynamic with the host organisation.

Experiences of oppression and power relations

Reflecting that PR phases are not mutually exclusive, co-researchers returned throughout the first part of this phase to talk more about experiences and problems discussed in earlier sessions. This repetition was an important way of validating data obtained earlier. Co-researchers talked further about: negative experiences at the local psychiatric hospital; problems with medication; problems with GPs; fears about being 'dropped' by community workers; isolation after hospital discharge; and the closure of the social services day centre.

Some additional points of discussion in relation to professional power were made during this phase. The first was co-researchers' observation of the small number of patients currently admitted to the local psychiatric hospital compared with previous years, and their view that people had been moved into the community with very little support: "with nobody to look after them, left to their own devices, nobody caring about them, what happens to them" (Rose). This comment reinforces observations in the literature that community care service provision had been inadequate to address the needs of people being discharged from institutions (Barham, 1997). However, such views also

appear to contradict Foucault's (1977) idea of 'generalised surveillance' operating within 'carceral societies' such that people feel they are constantly being monitored. These co-researchers seemed to believe that the opposite situation was the case, whereby service providers did not monitor people closely enough.

Another interesting point on professional power was Sheila's observation that her community care worker was putting pressure on her to 'respond' to activities under threat of losing the service, which she viewed as a 'Catch 22' situation:

> **...she says '...I've got to tell my leader what I'm doing with you, and if they say you're not responding... they'll pull me out'... and what happens if you do respond, come on well? They'll take her away anyway, won't they?! (Sheila)**

Sheila's insightful comments illustrate the way in which professional power can be exercised to withhold extremely valuable resources (Lipsky, 1980; Wilding, 1982). The imposition of professional definitions of need upon people, disregarding their own understanding of their situation and their wishes (see p.63-64), could also be detected in Sheila's concerns. Foucault's (1977) conceptualisation of surveillance of service users by professionals, often linked to normalising judgements (see p.57-58), is illustrated in Sheila's view that she was being monitored to see how well she was 'responding' to professional interventions, evaluated on the basis of professionally-defined criteria of 'progress'.

Section B: Researching reality and analysing data

This section describes and critically analyses the research phase undertaken by co-researchers, namely group interviews with professionals. A summary of session content is presented followed by interview findings, with critical interpretation of emergent themes. Reflections on the empowerment processes and power dynamics operating are then highlighted.

Content of sessions

A community psychiatric nurse (CPN) and a community care team leader (CCTL)[144] took part in the first interview. For ease of notation, the pseudonym of Vicky will be used to refer to the CPN and that of Sarah to refer to the CCTL.

The second group interview was with the local councillor whom Sheila had specifically asked to be invited (chair of the social services committee) and a health authority manager with responsibility for mental health services. The pseudonym of Andy is used to refer to the health authority manager and that of John to refer to the councillor[145].

After these interviews, Sessions 15 and 16 involved some analysis of interview data, preparatory work for the third interview, and planning for future interviews and group sessions. The fifteenth session also marked the start of work on Phase Five of PR, defining action to be taken.

The third interview was with a local GP, who was approached as Sue knew her and knew that she was interested in mental health issues. The pseudonym of Celia will be used to refer to the GP in this dissertation.

We started each interview with a round of introductions. I gave some background on our work, describing the process by which people came to join the group and the work that we had undertaken exploring people's experiences and identifying areas that we wanted to find out more about. I explained that co-researchers had decided that they wanted to ask professionals questions face-to-face.

I also focused upon confidentiality. I noted that interview information would be used by me for my PhD dissertation and might also be used by co-researchers, for example as

---

[144] Both professionals worked in a different area of the city to the area in which the service users lived (to avoid the possibility of service users having to challenge people upon whom they relied for a service).

feedback to other centre users, or as the basis for a newsletter article. However, we agreed that professionals' comments would be presented anonymously. I asked permission to tape record interviews, noting that the recording would only be listened to by me and that the transcript would be confidential to people involved in the project. I stated that co-researchers also wished their confidentiality to be respected, to ensure that their names were not used in any reporting of interviews and that their comments would not affect their treatment or access to services. We then started the interview, using a list of questions prepared in the group (topics of which had been sent to the interviewees in advance).

Interview findings

Co-researchers asked interviewees questions on a range of topics, including: inpatient psychiatric provision; community mental health services; needs assessment; GP practice in relation to mental distress; other support and activities (including work opportunities, day services, and transport); resourcing of mental health services; and service developments. Interviewees' responses are presented via the identification of themes and illustrative quotations, and are then critically interpreted. It should be noted that not all topics were covered in each interview, depending on co-researchers' wishes and the interviewee's particular job.

Inpatient psychiatric provision

Table 10 (p.260) provides examples and illustrative quotations of themes that emerged in response to co-researchers' questions and comments about the inadequacy of service provision at the local psychiatric hospital and negative experiences of care there.

[145] Both the health authority manager and the councillor stated that they were happy for their names to be used in any reporting of the research, but their comments have been anonymised here to maintain continuity throughout this dissertation.

Table 10: Interview findings on inpatient psychiatric provision

Theme	Source	Examples
Inadequacy of psychiatric hospital provision	Vicky Sarah Andy	• "I think there's been quite a lot of work done about security on the wards... but... a lot of those places like (local hospital) have been like that for donkey's years and you can't just change them." (Vicky) • Need to provide more single-sex wards (Sarah) • Need to review activities and build better links with community services (Andy)
Lack of support from nursing staff	Celia	• Such lack of support may be due to nursing staff changing over regularly on shifts, thereby losing continuity with 'patients' (Celia)
Psychiatric system encourages dependency and institutionalisation, but can feel safe	Vicky Celia	• "...because people were institutionalised, you weren't treated as an individual, but it was secure, it was safe... if someone's been in and out of hospital, it can become a habit." (Vicky)
Desire to avoid hospital admission by dealing with crises in community	Andy John Celia	• The health authority is establishing community 'crisis teams' to work with people to avoid hospital admission (Andy) • "...the straw that breaks the camel's back is some sort of practical problem... that's sortable, but because it's after 5 o'clock and there's no-one there, what do you do? It seems a bit ridiculous that you have to go into hospital because of that so we need to look again at what we're doing..." (Andy)

Interviewees acknowledged the inappropriate nature of the hospital buildings, and the lack of activities. The poor continuity involved in nursing staff working shifts in hospitals was also highlighted by the GP as a possible explanation for people's negative experiences of nursing care. While the old system of long-term hospitalisation was identified as inadequate, ignoring people as individuals and encouraging institutionalisation and dependency (Goffman, 1961), two interviewees suggested that this system felt safer for some people (which Mike confirmed during the second interview as his reason for desiring readmission to hospital).

John and Andy emphasised that service planners were attempting to avoid hospital admissions by establishing crisis teams working with people in the community to

identify ways of avoiding hospital admission and developing 24-hour support services. Their comments highlighted both their awareness that current services were designed more for the convenience and needs of professionals than of service users (Wilding, 1982), and their desire to make services more supportive and less 'disciplinary'.

Community mental health services and care planning

Co-researchers also asked questions about community mental health services, particularly in relation to care planning on discharge from hospital and levels of support from community professionals. Interviewees' comments on this subject are presented in Table 11.

Table 11: Interview findings on community mental health services and care planning

Theme	Source	Examples
Discharge planning does not always work and some people are left without desired support	Vicky Sarah	• "I wouldn't like to say that we have cracked it (discharge planning) yet." (Sarah) • "I think it's harder when you're in hospital for the first time to know exactly what will happen, it's trial and error sometimes, and... I've been in situations where I get told someone went home yesterday and can you see what they need, so it's not perfect." (Vicky)
Need to improve current care planning/ management system	Andy John	• "At the moment there's five different systems for care planning across our district... We need to make it simple so that staff can carry it through... but there is a long way to go." (Andy)
Lack of accessible information on available community services	Vicky Sarah	• "...once you're in 'the system'... you then have the knowledge about what services are available, but if you aren't or you're new... then I find that the dissemination or spread of information from statutory services... is very poor." (Sarah)
Inadequate community services in place to deal with speed of hospital bed closure	Vicky Sarah John	• Closure of hospital beds happened too quickly, without full assessment of alternative services available (Sarah) • "...until we can start slimming down the hospitals and releasing resources, we haven't really got the money to build up the community services... And there is still pressure on hospital beds, but that's because the community services aren't there! (John)

With regard to planning for hospital discharge, interviewees acknowledged that this system was 'patchy' and that while they were working to improve it, sometimes people were discharged before appropriate care and support was in place. Interviewees agreed that the existing care planning and management systems needed improvement, and that more resources still needed to be diverted from inpatient provision to enable implementation of improvements to community services.

Needs assessment

A specific element of care planning raised by co-researchers was that of needs assessment, in particular how professionals made decisions about what support someone needed and whether service users were involved in these decisions. These questions also related to co-researchers' concerns about losing sources of community support. Table 12 (p.263) summarises interviewees' responses on this issue.

Interviewees noted potentially differing interpretations of 'need' by professionals and service users, and acknowledged that professional definitions of need sometimes override those of service users (Wilding, 1982). However, the CPN and CCTL, for example, also demonstrated a desire to work in partnership with service users, adopting an empowering, strengths-focused approach similar to that discussed earlier in relation to social work practice (see p.83).

They also acknowledged tensions that might sometimes exist between professionals' and service users' views of risk, and potential constraints on professionals' capacity to work with a positive risk-taking model due to the prevailing 'blame culture' in society (Langan and Lindow, 2004). However, it was emphasised that assessments should also involve consideration of people's strengths and how to develop these.

Table 12: Interview findings on needs assessment

Theme	Source	Examples
Needs assessment (and service provision) might take longer if the service user is new to the 'system'	Vicky	• "When a new service user is seen for assessment, this is a very thorough and therefore time-consuming process but for people already known, assessment and service provision can be arranged more quickly." (Vicky)
Needs assessment should be done jointly by service users and professionals	Vicky Sarah Andy	• "… hopefully it's about a joint decision between yourselves and those people that are supporting you, as you move forward in your personal growth…" (Sarah)
Risk assessment is a subjective process, and professionals and service users may interpret 'risk' differently	Vicky Sarah	• "I think some of the aspects of the assessment are about looking at taking risks and people taking personal risks and the level of independence they can actually cope with… And I think that's a very subjective thing... it is often through trial and error." (Sarah)
Tensions exist between providing support and encouraging independence	Vicky	• "…it's somehow getting the balance between being supportive and helpful without taking over somebody so they don't have any power left and then don't feel like they can do anything for themselves." (Vicky)
Tensions arise between service user and professional definitions of 'need'	Vicky Sarah	• "…while there is a need, then it's assumed that a service will be offered, and when a decision is made… and a service *isn't* offered… Your interpretation of need may be very different from the people that are offering the service, and I think this is where lots of frustration and anger erupts from." (Sarah)
Resource constraints mean professionals often cannot provide ongoing support	Vicky John	• "In an ideal world, we could work with people over a period of time until they were feeling OK and basically didn't need any support, but that isn't actually always possible." (Vicky) • "…the problem, to be honest, is that we haven't got enough social workers to attach somebody to all those people who've had mental health problems on a kind of permanent basis, so we have to use those social workers primarily at the point when big change is going on for people to help them plan those changes, put the services in place, and then they move on to the next person, because you know there's someone waiting behind you." (John)

The assessment-orientated social work role described by John has been identified by Dominelli (2002:32) as potentially impeding the social work profession's desire to build relationships and work closely with service users to promote change. Such constraints are also likely to be applicable to other community professionals such as CPNs, working with high caseloads across large areas.

John also suggested that if people were in regular contact with day services, their need for a social worker should lessen because day workers would notify the social services department of any problems. John was therefore implying a surveillance role for centres such as the host organisation (Foucault, 1977), which was likely to be at odds with service users' desires to have a safe space where they could talk to people about their feelings without fear of being monitored and assessed.

GP practices in relation to mental health

The GP interview differed from the others in that co-researchers tended to ask more specific questions about the GP's work and role, and about the nature of mental distress (although co-researchers did touch upon some of the topics discussed in previous interviews). This section of findings therefore relates only to the GP interview, and covers different elements of GPs' work with people in mental distress. These themes are summarised in Table 13 (p.265).

The range of areas in which Celia worked with people in mental distress confirms the GP's key role in mental health service users' lives (as highlighted on p.69). As such, GPs are in a position to use their professional power productively, to access resources and services for people.

Nonetheless, Celia's comments also highlight the considerable 'power over' people exercised by GPs, for example in their power to remove people from their practice lists. Being able to use police cells as a place of safety was another example of such power

exercise, although Celia acknowledged this was "the absolute last resort", highlighting an awareness of the frightening and disempowering nature of such an experience.

Table 13: Interview findings on GP practices in relation to mental health

Theme	Examples
The GP's role in relation to mental health	• The GPs' role includes: identifying mental distress and assessing its severity; listening to people, helping them to explore their own ways of coping, and putting them in touch with other support; caring for mental health service users in local supported housing; attending case conferences and care plan meetings; and occasionally visiting the local psychiatric hospital to see patients (Celia)
The GP is the first 'port of call' during the day and at night, but is likely to refer people on to specialist services	• "Some people may need social services… some people may need an assessment from a mental health team so that we know how to help them… You see, a psychiatrist or a CPN *will* have more time, *is* more experienced than me, so I respect that." (Celia)
GPs do have discretion to remove people from their 'list' (e.g. if misusing the emergency service)	• "…we still have discretion to ask someone to leave the list if we can't handle it for one reason or another, or they've moved out of the area, but not for no reason at all." (Celia)
There is a need for A&E and emergency GP staff to be trained in dealing with panic attacks	• "…it sounds like there's a whole lot of people who perhaps could do with some more information about panic attacks so that… instead of just getting angry, they could be straight with you and give you some more information." (Celia)
GPs only have limited time to spend talking and listening to 'patients'	• "…there are quite a lot of people who… I will see through their troubled time, but I cannot provide much time… appointment times are ten minutes on the computer… It's quite hard to know that you're keeping patients waiting." (Celia)
GPs do sometimes have to use police cells as 'places of safety' if hospital beds are not available, to manage crisis situations	• "…a patient of mine also needed help desperately and there weren't any beds in (city), the nearest was (city 100 miles away)… the let out was police. And it sounds awful, but it was a place of safety, that was what the person needed. If things blew up and went terribly wrong and there still wasn't a bed in the hospital then all we had recourse to was a place of safety." (Celia)
GPs do not automatically consider the needs of 'carers' when dealing with people in mental distress	• "…we always think we're the patient's doctor. We're not the carer's doctor. If they need some help, we I suppose would expect them to come in their own right to us and say 'I want some help from you'… So I would say there's a gap there." (Celia)

Co-researchers also used the GP interview to obtain more information about their specific experiences of mental distress[146]. Co-researchers' conceptualisation of their distress using medical discourse was again apparent, and was inevitably reinforced by the doctor's use of medical terminology such as 'illness' when referring to distress.

Other support and activities

Other services and activities that co-researchers raised or discussed with interviewees included day services, transport, work-type opportunities, and befriending schemes. Themes highlighted by interviewees in these areas are outlined in Table 14 (p.267).

With regard to the closure of the social services day centre, John identified social services' perception that such institutions created dependency amongst service users, which they wanted to reduce to encourage people to live more independently. Nonetheless, he acknowledged that the decision was also resource-driven, due to inadequate resources to meet demand for services.

John's comments about social services providing funding to subsidise taxis (which were a critical factor in co-researchers' subsequent action) were made after co-researchers made clear to interviewees problems they were experiencing in reaching the drop-in centre. Co-researchers' comments challenged professionals' assumptions that a centre would be 'accessible' if it was what they perceived as 'local' (even if public transport functioned in such a way that it was very difficult for people in the local area to travel by bus directly to the drop-in centre). This was acknowledged by the health authority manager, whose comments exemplified the way in which professional power to determine policy and resource allocation might lead to services being organised according to professional need and interest rather than service user need (Wilding, 1982).

---

[146] For example, Rose asked the GP to explain the difference between the diagnoses of 'manic depression' and 'schizophrenia', and Amy talked about her diagnosis of 'obsessive compulsive disorder' (OCD), the disabling effects of these feelings and their impact on her husband. Rose and Sheila talked about how difficult mental distress was, as it was not visible in the same way as physical illness.

Table 14: Interview findings on other support and activities

Theme	Source	Examples
Reasons for closure of social services day centre	John	Reasons for this decision included that: • the day centre was for the whole city, so many people had to travel a long way to use it; • the buildings were very old and inaccessible; • the centre was not an efficient use of resources; • the social services department wanted to encourage people to use specialist services only when they needed to rather than 'out of habit'; • its replacement with four local drop-in centres would make services more accessible. (John)
Better transport arrangements are needed to enable people to attend the drop-in centre	John	• "...often for the council, taxis are cheaper than specially adapted vehicles with drivers who aren't always used very efficiently, which is why I think if you're saying (the subsidised council transport scheme) is unreliable and you can't get to the service on the planned days... the city council would pay (the host organisation) for the cost of it and it may be worth looking at whether a taxi would be a more suitable arrangement." (John)
Service planners do not necessarily consider all issues relevant to service users (e.g. transport) when deciding where to locate a service	Andy John	• "I think part of the problem is when you start to see this, you think 'Oh that's not the best place to put things', and it's only by starting to do this kind of work and getting closer to where people live (that you realise this)..." (Andy) • "(the subsidised council transport scheme) isn't a social services activity, but it's obviously crucial to you in terms of your social services support." (John)
Lack of befriending schemes for people in mental distress	Vicky Sarah	• Difficulties and time are involved in identifying "the right sort of person to do that and give them training." (Vicky)
Lack of work-type opportunities for mental health service users	Vicky Sarah	• "The two areas I think which are missing are the befriending... but also... some work-type scheme... so that people can feel valued and that the skills they have are valuable... we don't have that..." (Sarah)
'Benefits trap' for people wanting to work	Vicky	• "...if you start to do something then your benefits get affected, don't they? If you earn more than £15 a week, you end up losing money, and I think that's a really impossible Catch 22." (Vicky)
Development of LETS is required for people to enhance skills while avoiding losing benefits	Vicky Sarah	• "I know there are some schemes... where people can trade skills... so there's no money changed hands but you would feel you were using some skills that you were good at..." (Vicky)

In relation to work-type opportunities, Vicky and Sarah confirmed empirical evidence of the lack of employment opportunities for mental health service users (Oliver et al, 1996) and the financial disincentives to work created by the benefits system (Secker et al, 2001).

Resourcing of mental health services

Co-researchers specifically asked interviewees about whether mental health services received a fair allocation of resources compared with other health and social care services. Table 15 presents interviewees' responses.

Table 15: Interview findings on resourcing of mental health services

Theme	Source	Examples
Mental health services tend to receive less funding if located within general NHS Trusts	Andy	• "...things like surgery and super-specialities tend to pull a lot more money, whereas community services and mental health tend not to do so well in the pecking order in a Trust." (Andy)
Mental health services do not receive as many social services resources as other services as they are seen as the health service's responsibility	John	• "(Mental health) really is quite a Cinderella within our services, partly because the main responsibility has always been seen to lie with the Health Service..." (John)
Mental health services are not as well funded as other local authority services because they do not attract much public interest	John	• "When I knock on doors as a councillor, trying to persuade people to re-elect me, I've never ever once in ten years had anybody say to me 'What are you doing around mental health services?', whereas I have had people asking me about services for elderly people, services for children, and education." (John)

John and Andy's frank comments on the relatively poor status and therefore resourcing of mental health service provision within their organisations reflect empirical findings that mental health service users are stigmatised and viewed as 'deviant' by the general public (Leff et al, 2000; Salter and Byrne, 2000) and therefore do not receive as much public support as more 'worthy' disadvantaged groups.

Service developments

In discussion, interviewees highlighted areas (summarised in Table 16) where services were being developed to improve service users' experiences.

Table 16: Interview findings on service developments

Theme	Source	Example
24-hour services are being developed to support people in crisis	Vicky John Andy	• "...you might become very anxious at 11 o'clock on Saturday night, and it's no good being told that there's an office open... on Monday... the idea is that there will be good crisis support on a 24-hour basis, so that people... can actually call on some emergency support at that point in time." (John)
'Places of safety' are planned to provide alternatives to hospital for people to take 'time out'	Vicky John	• "One of the things we want to develop jointly are emergency houses which are... a safe place... where people can basically say 'I'm in a terrible state, I don't need to go into hospital... but I do need a place of security..." (John)
Health and social services might merge budgets to create one integrated mental health service	Andy John	• "...we might well decide that we put all our money (and) all our staff into one pot... so... you've actually got one integrated service. I hope we're going to end up there." (John)

Interviewees therefore demonstrated awareness that services needed to change to focus more on service users' desires and needs, rather than continuing with traditional patterns of provision based on professions' needs and interests (Wilding, 1982).

In addition to analysing interview content, empowerment processes and power dynamics operating are of critical importance in the context of this doctoral work, particularly in the light of earlier discussions about professional power.

Processes of empowerment and power relations in PR

Individual participation and empowerment processes

At the first interview, co-researchers were initially very nervous about asking questions but all contributed (except Maria) once they became more comfortable. Rose tended to speak the most, and Amy also made considerable input. Sheila was quiet at first, but did ask about community care workers withdrawing services. Mike and David made some input, but Maria made very little contribution.

Co-researchers made significant contributions at the second group interview: they were forthcoming in asking questions and seemed relatively comfortable engaging in dialogue with the interviewees. Sheila's contribution was particularly significant, as in earlier sessions she had stated that she would be too nervous to ask questions. However, she did question John about the day centre closure and challenged interviewees on their comments about encouraging independence from services. In the review session after the interview, Sheila was pleased that she had asserted herself in this way, commenting "I don't know what came over me!". This interview was evidently a positive and potentially empowering experience for her in terms of increasing her confidence and developing a more positive self-definition.

All co-researchers participated in the third interview, including Maria. With regard to individual empowerment processes, the most important aspect of the interview seemed to be the way in which it gave co-researchers the opportunity to obtain desired information on their personal issues. The GP took time to ask Maria questions and to encourage her to talk and interact, which appeared to be a very positive experience for Maria[147]. This validation of her experiences and feelings by the GP seemed to boost Maria's confidence.

---

[147] Maria was extremely pleased with this interview, and approached Celia afterwards to shake her hand and thank her for the interview.

With regard to elements of individual empowerment processes (see p.201), the interviews therefore appeared to enable most co-researchers (with the possible exception of Maria) to obtain desired information (for example on transport and service developments), enhance their skills and abilities (by interviewing professionals and interacting with them in such a forum) and assert their personal needs (as co-researchers made it clear to interviewees what sort of services they felt they needed).

Group empowerment processes

In relation to group empowerment, the interviews acted as a forum for co-researchers to participate jointly in an activity aimed at obtaining valuable information. This appeared to help co-researchers to experience a sense of 'working together' with a view to taking action to achieve changes in resource allocation, and could thus be viewed as contributing to group empowerment processes. Indeed, when co-researchers discussed the interviews over coffee breaks, they were full of enthusiasm and interest after the experiences and continued to debate issues raised.

Operation of power dynamics in PR project

Between co-researchers and interviewees

Interaction at the first interview was initially stilted, partly due to co-researchers' nervousness and hesitancy in asking professionals questions in this forum, but also to the apparent unease of one of the interviewees at being in front of the group. Interesting power dynamics were therefore operating, with both co-researchers and this interviewee feeling apparently powerless when faced with one another in such a situation. Mike interrupted Sarah very early in the session, challenging her authority by stating "You don't seem to do much for anybody... do you?". Once co-researchers became less nervous, the interview flowed well and co-researchers became increasingly confident in questioning the interviewees.

Power appeared to be relatively evenly shared during these exchanges, partly due to the non-threatening and supportive approach adopted by the interviewees. It appeared that Vicky and Sarah's stated approach to working with people with experience of mental distress, namely a partnership, strengths-focused and empowering one, prevented a more noticeable power imbalance which might have been evident with professionals used to working in a more traditional and paternalistic way.

The group was more confident from the start of the second interview than they had been at the first, and asked the interviewees questions that led to extensive and interesting discussions. The two interviewees, Andy and John, appeared to be attempting to minimise the 'professional/service user' power imbalance by adopting an informal and approachable interactional style.

Although there was an element of deference in some of the co-researchers' questions to the interviewees, possibly reflecting perceptions of professionals' supposed expertise and knowledge (see p.67), there were also occasions on which co-researchers were assertive in stating their opinions and challenging interviewees. For example, both John and Andy emphasised their organisations' desire to encourage people to become more independent and to access 'mainstream' community and leisure services rather than statutory mental health services. However, Sheila challenged them on the reality of this aim:

John **If from day care you can actually start to engage in other things outside the day care, you might become less reliant on it...**

Sheila **Well is it so bad if we are reliant on it, if the alternative was going in hospital or staying in bed?**

John Well if that's the alternative, I agree...

Sheila **I am reliant on day care services, I was reliant on (the central day centre)... and yet that kept me from the way of life I had before. I had no quality of life before... I was in one room all the time, I never went anywhere...**

Sheila's challenge was important in highlighting that if service users feel that dependency has been created after years of service use, professionals' attempts to reduce such dependency should be made in a way which is experienced as supportive rather than as threatening or punitive by service users.

At the third interview, the group seemed relatively confident asking the GP questions and talking about their experiences (although David became very nervous when she addressed questions directly to him). Nonetheless, despite Celia's relaxed and informal manner, strong power dynamics were still evident between the GP and co-researchers. The way in which co-researchers talked to the GP was far more deferential than their approach in the previous interviews, demonstrating their awareness of the doctor's status, powerful position and medical 'expertise' (see p.68). The structural element of the GP's power, as a member of one of society's most powerful institutions, also contributed to the power dynamic operating in this situation.

Although this session was an interview in the sense of co-researchers asking questions and obtaining answers, it was also at times a discussion between co-researchers and the GP. It was clear that co-researchers greatly appreciated the opportunity to obtain information from a GP in this way. Similarly, while the GP answered co-researchers' questions fully, she was also interested in people's experiences and asked co-researchers several questions. I felt that this reflected the importance of dialogue as a way of building knowledge, as emphasised in PR (Finn, 1994), and reinforced the value of co-researchers' own experiences and knowledge.

Between research student, project worker and co-researchers

I 'chaired' the interviews (at the request of co-researchers), introducing the group's work and providing some initial structure. Although I found myself asking some questions at the start of the first interview to encourage its flow, once co-researchers began to engage in the interviews my intervention was not necessary and I played a low-key role. Similarly, Sue took a 'backseat' in the interviews, only commenting occasionally to give

specific pieces of information. The interviews were very much driven by the co-researchers.

Between research student and host organisation

During this phase, Sue informed me that she was experiencing pressure from her manager to move the timing of our sessions to enable co-researchers to attend the centre users' meetings first. Although co-researchers had already stated a preference for an earlier start, when they were offered this choice David suggested that the PR group should support the users' meeting and it was subsequently agreed to delay session start times.

This incident demonstrated the constraints of working with a group of service users identified as 'belonging' to an organisation, and the organisation's perception that their needs should then override service users' wishes. However, I was conscious of the fact that the centre was under-staffed, and that the group took away one-third of the centre's staffing resource (i.e. Sue) during their busiest afternoon every week. I was also aware that it might be valuable for co-researchers to attend the centre users' meetings to further develop their confidence and skills, and as a potential forum for continuing with activities arising from our research once my involvement came to an end. Nonetheless, I was clear that in line with PR methodological principles, co-researchers should be enabled to decide for themselves how and when they wanted our sessions to take place.

Following my discussions with the host organisation manager, she did start to take a more positive role in relation to our group's work, for example by speaking to the council subsidised transport scheme about problems that co-researchers had been experiencing trying to access their service. Since the new manager had arrived, service users were also being consulted more on the drop-in centre's activities and were playing a far more active role themselves in its day-to-day running. I felt that the more participative environment developing in the centre was positive for the PR group, in that it might have been contributing to co-researchers' increased willingness to make

decisions and might also have provided an opportunity to continue the group's work beyond the life of our project.

In addition to these observations of empowerment processes and power dynamics occurring, important issues in relation to the application of PR methodological principles also arose and are analysed in the following section.

Section C: PR methodological principles in practice

This section presents consideration of the extent to which Phase Four succeeded in adhering to PR methodological principles of facilitating: processes of social investigation, education and action; participation by co-researchers; and a new role for the 'external' researcher[148].

Processes of social investigation, education and action

Throughout preparatory sessions, co-researchers returned to talk about experiences and problems discussed earlier. Indeed, it was sometimes difficult to encourage co-researchers to move beyond these discussions to focus upon the next phase. Nonetheless, these continuing discussions were valuable in enabling co-researchers to share experiences and learn from one another.

The interviews clearly functioned as opportunities for 'social investigation', as co-researchers found out more about issues that concerned them. In addition, they gave co-researchers the opportunity to share their experiences with professionals, thereby providing the basis for subsequent action. Indeed, the interviews tended to develop into more of a discussion than a formal structured one-way interview, which I felt reflected

[148] Issues of power redistribution and control in favour of co-researchers have already been covered in discussion of power dynamics earlier in this chapter.

PR's ethos and the value placed upon co-researchers' own experiences. Furthermore, co-researchers' comments did lead to action by professionals in some cases[149].
We had a 'debriefing' session after each interview (as they tended to provoke further discussion)[150], thereby continuing the educational process for co-researchers. These sessions also allowed co-researchers to reflect on the interview process. Co-researchers were very pleased with the interviews, viewing them as positive experience during which they had been listened to.

The 'action' phase of the PR project also started to occur during this phase. In discussion after our third interview, Sheila was very animated about the possibility of subsidised taxis and asked if we could write a letter to the councillor. We spent time drafting a letter stating that no-one in local community mental health teams knew about funding for free taxis and asking how co-researchers could obtain subsidised taxis as he suggested. The start of this action process was extremely positive, not least as it was instigated by co-researchers and thus reflected PR's aim of placing control with co-researchers.

Maguire's (1987) description of her PR project demonstrated that she viewed Phases Three to Five as occurring concurrently rather than sequentially. This proved to be the case to a certain extent in our project, in that co-researchers both continued to discuss their experiences and started to think about Phase Five while still involved in Phase Four.

---

[149] For example, the GP telephoned me after the interview to say that she had fed back key points from the interview to the other GPs in her practice, and they felt that the issue of advice on panic attacks should be good clinical practice. She was also intending to raise the issue with the local emergency GP service. Celia also informed me that she had left a message for her friend who was in a self-help group for people with OCD to find out more about this group for Amy, and was waiting to receive a response.
[150] Discussion took place on issues including befriending schemes, housing, physical problems aggravating mental distress, GPs and the development of primary care groups, GP expertise in mental health, and provision of information to people to enable them to make choices about services.

Participation in all stages of research process

During this phase, I worked with co-researchers to decide upon a research design and areas to be investigated, gather information, and to a lesser extent analyse that information. We also began to use information obtained via interviews to develop strategies for action, to achieve improvements in people's lives.

Co-researchers' participation in preparatory stages of this 'research' phase was tentative, in that they were unsure what activities they could undertake next. However, once I had explained to co-researchers possible research methods to use to obtain information, their participation in decision-making processes about the research increased, and continued to do so throughout this phase[151].

Maguire (1987) noted that co-researchers started to take control over group membership during the fourth phase. Similar moves occurred in our group, with David joining at the request of Sheila, and co-researchers having ongoing discussions about whether they should open up interviews to other centre users.

When the interviews took place, although I 'chaired' them to keep to time, co-researchers very much took the lead in questioning interviewees and determining the direction of interviews. Their participation in this phase was therefore towards the maximum end of Arnstein's (1969) ladder of participation (see p.101).

Part of this research phase involves analysis of information obtained. At our fifteenth session, held after the first two interviews, I aimed to encourage co-researchers to reflect upon interviewees' responses i.e. to analyse the data collected.

---

[151] For example, co-researchers decided on their preferred research method (group interviews), which professionals they would like to interview, the timing and location of these interviews, and the number of interviews they wanted to hold. They also discussed issues about which they would like to ask professionals questions, and from these discussions we developed and refined a list of questions to act as a 'topic guide' for the group interviews (Appendix 5).

Although I had prepared a sheet of main themes from interviews, co-researchers appeared to find it hard to critically analyse what interviewees had said, instead tending to comment further on issues raised. Nonetheless, co-researchers did undertake some analysis of interviewees' comments. Rose felt that mental health services were seen as a 'Cinderella' service due to stigma, and that health services wanted to keep people out of hospital and in the community as this was cheaper for them. She also commented on the apparent lack of community care services in their local area, compared to the area in which the CPN and community care team leader worked. When Sue commented that people tended to work more closely together in that area, Mike stated that it was better when health and social services worked closer together. Rose felt that it was unfair that one area should be receiving better services than other areas, and hoped that this situation would improve when services merged into one Trust.

New role for 'external' researcher

Similar to Maguire's (1987) observation that she continued to be "the organizer and mover of the group" (p.163) during the fourth phase, I was also involved in considerable 'background' organisational work corresponding with professionals to arrange interviews. Maguire found that co-researchers were participating more in discussions but were not necessarily prepared to take on organisational roles, which again mirrored my experience. For example, none of the co-researchers wanted to chair interview sessions, or lead a planned presentation of the group's work to other centre users[152]. They still looked to me to undertake such roles, possibly due to a lack of confidence or experience of speaking 'publicly' in that way, or possibly as they perceived this to be my role within the group which they were not interested in taking on.

[152] In the event, the presentation to other centre users did not take place, as Sue was on sick leave on the planned day and had not arranged for us to have time to talk at that meeting, and co-researchers had still not agreed amongst themselves whether they wanted the interviews with professionals to be open to other centre users.

Like Maguire, I also found the need to remind myself "not to make unilateral decisions for the group" (1987:163) between sessions. For example, one interviewee asked to see the interview schedule in advance, and I almost agreed to do this before remembering that it was important to ask co-researchers whether they were happy with this. Co-researchers actually felt that they wanted to have an element of 'surprise' in the interviews, and so decided to send out only possible themes to be discussed in advance, which reminded me of the importance of involving co-researchers in every detail of the research process to enable them to have control.

Conclusion

Processes of empowerment

The research undertaken during this fourth phase of our project was very successful, both in terms of the interview data gathered and in terms of co-researchers' development and their growing confidence working together. Co-researchers obtained valuable information from the interviewees, for example about reasons for the day centre closure, possible transport provision, community care services and assessment systems, and positive developments in mental health services. They were also able to gain information that was important for their personal circumstances.

The interviews were at times two-way discussions rather than one-way formal interview situations, with both co-researchers and professionals using them to obtain information and to give their views on issues raised. Although this scenario therefore differs from traditional definitions of a research interview, I feel that this approach was entirely appropriate within the PR framework, which emphasises the value of co-researchers' own experiences and the importance of dialogue as a means of knowledge production (see p.167-168).

The investigation in which co-researchers engaged, via interviewing professionals, could therefore be seen as contributing to their individual empowerment by developing their

knowledge (and to an extent their research skills), asserting their personal needs and enhancing their sense of personal power and confidence, and to the group's collective empowerment by providing the basis for social action (particularly on the issue of transport). Consciousness-raising (identified as a strategy for empowerment) took place, for example co-researchers learning more about how their experiences linked to policies of community care provision and service closure.

Power relations

Foucault's (1998) assertion that power is exercised in all social relations was clearly relevant during this phase, with power relations operating between all parties involved. Furthermore, the power dynamics occurring during interviews were interesting, with a less marked power imbalance between co-researchers and interviewees than might be the case in a 'professional/service user' interaction yet still some element of deference to the professionals' structural authority and expertise (particularly in the case of the GP).

The inherent difficulties involved in working with a host organisation were also highlighted, in terms of achieving a balance between drawing upon the host organisation for support and resources and separating the group's activities sufficiently from the host organisation's agenda for the group to feel 'independent'.

PR methodology in practice

In Phase Four, co-researchers fully participated in carrying out research as emphasised in the PR literature, deciding on research methods to use, who to invite to be interviewed and how interviews would be conducted, preparing questions to ask interviewees, and carrying out the interviews. My role was to undertake background organisational work to arrange interviews, leaving co-researchers to drive the interviews' direction and content. Co-researchers were participating more in discussions during this phase but did not want to take on organisational roles, for example chairing interviews or presenting their work to other centre users, leading me to conclude that the methodological

principle of co-researcher control of the research process could not be imposed upon co-researchers. Rather, opportunities for co-researchers to take control should be made available, for them to choose to take up if they so wished. Nonetheless, all co-researchers demonstrated increasing confidence during this phase, both in decision-making and in interviewing professionals, demonstrating that they were beginning to take control of the research project as advocated in the PR literature.

It was also clear that the provision of adequate time to prepare for carrying out research was a crucial aspect of the PR process, to enable co-researchers to feel confident in undertaking research themselves. Maguire (1987) does not address this issue in any depth, and therefore neglects a vital aspect of PR.

It was not possible to keep the phases of PR separate, as co-researchers returned at every session to continue their discussion and exploration of their experiences as people using mental health services, and action in relation to improving their circumstances (Phase Five of PR) started to occur while this fourth phase was still underway. This finding demonstrates that identifying distinct phases of PR was useful as a framework within which to work, but that it was important within this framework to maintain a flexible approach depending upon co-researchers' wishes.

Data analysis

Initial attempts to analyse interview data with co-researchers achieved limited success in interpreting the data. Instead, co-researchers used the data to further discuss and explore their experiences and issues raised in earlier phases of the project. Their primary use of the data was to take action to improve the transport situation, leading me to conclude that the main purpose of data analysis during a PR project, namely developing understanding as a basis for action, was likely to be different to that of analysis undertaken as part of more 'traditional' research projects.

This phase led into Phase Five, as co-researchers began to contact community workers to discover more about the availability of subsidised taxis suggested by the councillor. This fifth phase of the project, defining and taking action, is critically analysed in the following chapter.

Chapter Nine: Taking Action

Introduction

This chapter describes Phase Five of our PR project, which involved the group working together to define and take action on the issue of subsidised transport raised during group interviews. Co-researchers took a range of positive actions, including lobbying the social services department concerned, speaking at a Project Advisory Group (PAG) meeting, undertaking a survey to reinforce their action, asking the host organisation to lobby on their behalf, and analysing and interpreting correspondence. Access to benefits advice for centre users was also improved as a result of the co-researchers' contact with social services staff.

The first section of this chapter briefly describes the content of the seven group sessions that took place during this phase. The chapter then goes on to consider the way in which PR methodology functioned in practice during this phase, in relation to processes of social investigation, education and action, co-researchers' participation in all stages of the research process, and the 'external' researcher's role.

The third section of the chapter critically explores empowerment processes occurring both for individual co-researchers and for the PR group as a whole, and power dynamics operating between all parties involved.

Content of sessions

Sessions 18 and 19 aimed to update co-researchers on the transport issue and to consider the group's progress and future direction. This latter aim was not possible, however, as few co-researchers were present at these sessions and they wanted to wait until all co-researchers were in attendance to make decisions about the group's future.

In contrast, Session 20 was well attended, and co-researchers made decisions about the group's future direction and action they wanted to take. Sessions 21 and 22 were similarly vibrant meetings at which the group enthusiastically took action on transport, writing letters, planning a transport survey, inviting a social services manager to a meeting, and agreeing to involve other day centre users in this process. Co-researchers were full of energy, working together to take action to improve their situation.

In contrast, Session 23 was a far more subdued session attended by fewer co-researchers, at which a feeling of 'going round in circles' began to prevail. More correspondence with and feedback from the social services department on transport was discussed, and co-researchers continued to talk about their difficulty with transport and their need to attend daytime services. I also introduced the idea of the group's imminent ending.

At Session 24, the transport survey suggested by co-researchers was conducted with other centre users, albeit by Sue and me rather than by co-researchers themselves. Nonetheless, the two co-researchers present did briefly analyse the survey results with me.

PR methodological principles in practice

This section critically analyses the way in which PR methodology functioned in practice during this phase, particularly in relation to processes of social investigation, education and action, co-researchers' participation throughout the research process, and the 'external' researcher's role.

Processes of social investigation, education and action

This was the action phase of the PR project, and co-researchers engaged in various activities aimed at improving their circumstances. These activities are briefly described in this section to illustrate ways in which co-researchers engaged with this phase.

Much of this action involved correspondence between co-researchers, myself (on behalf of the co-researchers) and the local authority's social services department. Both Sheila and her social worker wrote to the councillor who was interviewed (John) informing him that they had been unable to find information on council subsidisation of taxis, and we drafted a similar letter in the group. We analysed the councillor's response (received soon after) together. His letter included a statement that previous social services policy to provide transport had been reversed in order to provide more funding for direct care options, and that transport would only be provided if service users were unable to use more 'independent' forms of transport. However, he also acknowledged that difficulties for people in reaching the new drop-in centre at its chosen location had not been understood and addressed adequately.

Co-researchers also spent time reading and analysing a letter that I had received from a social services senior manager in response to our correspondence with the councillor[153]. They all wanted to reply to this letter to make it clear to the senior manager that they were unhappy about both its content and its "patronising" and "offensive" tone.

Both Rose and Sheila felt that the letter had created additional anxieties rather than contributing to solving their identified problems, mainly as the senior manager commented in the letter that the council would prefer people to access mainstream

---

[153] This letter from the social services senior manager made three main points. Firstly, she acknowledged that the host organisation drop-in centre was not accessible for a large number of people living in its 'catchment area', and that this should be resolved by the host organisation developing outreach services. Secondly, she stated that she wanted mental health day services to follow the model being developed for people with learning difficulties, namely supporting people to use community facilities direct from home rather than going through a centre. Thirdly, with regard to transport she stated that social services staff were working with the council subsidised transport scheme to encourage them to be more flexible in their service provision, and that staff would also put individuals in touch with the council's Income Maximisation Unit to ensure that people were obtaining maximum benefit entitlements to enable them to better afford taxis.

community facilities instead of using day centres or drop-in centres regularly. These comments triggered anxieties amongst co-researchers about losing another source of support, and Rose, Sheila and Mike all emphasised that they looked forward to attending the drop-in centre as a place where they could be in company and feel safe (see p.189 for similar comments in the literature).

With regard to the manager's comments about encouraging people to use community facilities, such as college evening classes, both Amy and Sheila stated that they would not feel safe or comfortable in such situations. The council's Income Maximisation Unit was also highlighted as a resource in the letter, to maximise people's receipt of benefits, but Amy noted that this unit was based on the other side of the city and would be difficult for co-researchers to access.

We agreed that I would draft a response to the manager's letter based on people's comments. We also decided to include in this letter an invitation to the manager to discuss the issue with the group in person. Sheila stated that she felt the group should involve other centre users in this issue, by asking for their comments on the letter, and by inviting them to attend a meeting with the social services manager.

Analysing this letter led to further discussion of the nature of the drop-in service provision, transport, and support for people to maximise their benefits, demonstrating that earlier exploration of experiences and issues was still occurring to some extent during this phase.

Co-researchers also raised the issue of transport at a meeting of the host organisation's Project Advisory Group, with statutory organisations involved with the drop-in centre, but the social services link officer present stated that the drop-in centre service would never be like the free transport service provided by the closed day centre. Co-researchers drew their own conclusions from these comments:

Rose They keep passing the buck to everyone.

Sheila And what they're saying is... 'If you really want to come here, you'll spend the money', that's what they say.

I shared co-researchers' frustrations at the lack of positive results on transport during this phase. However, a positive outcome of the group's correspondence with social services was that the host organisation contacted the Income Maximisation Unit mentioned in this correspondence, and their staff agreed to provide an outreach service at the host organisation drop-in centre. This action illustrated the way in which links between our PR group and the host organisation helped to facilitate our action and obtain positive benefits for co-researchers and other service users.

A further piece of positive action was instigated by Amy, who commented that it would be useful to carry out a transport survey to provide information to help organise a driver scheme:

> Doing a survey you could actually find out, say there's a majority of people that come from (local area), it would give you a bit more concrete evidence as to where people are coming from and how much they spend and how they're getting there. (Amy)

I also suggested that if we did such a survey, we could show the results to social services staff to reinforce our argument about the need for an effective subsidised transport scheme. Co-researchers all felt that such a survey would be valuable, and we therefore drafted and agreed a questionnaire. When I asked co-researchers if they thought that people would be happy to complete the questionnaire, Rose and Sheila both said that they did not like forms. I therefore suggested that we could work with people to fill in the forms during one of our sessions, which both Rose and Mike felt was a good idea.

We carried out this transport survey with seven drop-in centre users during one of our sessions (with five completing the questionnaire on their own and two filling in the answers with me). Sue had also asked service users at the drop-in centre's outreach session to complete questionnaires, so together with those already completed by co-

researchers we had a total of 23 completed questionnaires. After the session administering the questionnaires, we spent a brief period interpreting the results together.

Co-researchers also expressed a desire to interview more professionals and service user organisations. I attempted to arrange this, but it proved impossible to organise further interviews during the life of our project[154]. However, I suggested that details of potential interviewees could be given to the host organisation to set up sessions through the centre users' meetings, and that I could still attend those sessions to support co-researchers if they so wished.

At one of our later sessions, I informed co-researchers about a conference I had been asked to attend to facilitate a workshop on the project, and asked whether any of them would like to attend with me. All of the co-researchers expressed interest in coming, and we therefore agreed that I would telephone the conference organisers to find out whether enough spaces were available for the whole group to attend with me. However, I was only able to take one co-researcher as the conference was fully booked, and co-researchers decided that David should attend with me.

It can therefore be seen that, in line with PR methodology, a range of action-focused activities took place during this phase, most of which were instigated by co-researchers. Investigation, in the form of developing and carrying out a questionnaire survey on transport, also occurred.

---

[154] The manager of the local psychiatric hospital did agree to be interviewed but the date on which she was available was a date on which Sue had organised something else (a tension discussed later in this chapter). With regard to local service user groups, I received no response from the patients council at the local psychiatric hospital, and received a message from the local mental health user forum saying that they were unable to come at the moment due to staffing difficulties.

Participation in all stages of research process

After a hesitant start to this phase, with only one or two co-researchers present at group sessions, co-researchers came together at the twentieth session to review the PR group's progress and to make decisions about its future direction and purpose.

This review session was a good opportunity to put decisions about the future direction of the group to co-researchers, to encourage them to decide what they wanted to do. Amy, Mike and David all stated that they wanted the group to continue meeting. For David this was because he had only recently joined, while Amy stated that "I need to get out, and if something's worth fighting for...". They decided that they would like to interview more people (in particular someone from the local psychiatric hospital, and people from the local mental health service user forum and the local psychiatric hospital's patients council). Amy stated that being involved in interviews was "a good confidence booster... you're actually doing something, you're confronting them and... finding out straight from the horse's mouth", demonstrating that she found participating in such activities empowering in terms of increasing her confidence and obtaining information.

Despite their participation in making decisions at this session, co-researchers were still quite deferential to me and often asked what I wanted to do, which I felt was partly because they were conscious of the demands the work made on me and partly because they were not used to being given the opportunity to shape activities in which they were involved. Nonetheless, co-researchers participated in a range of actions following this review session (as discussed above).

Maguire (1987:175) identified positive moves in group control and leadership during this phase of their PR project, while continuing to encounter variability in co-researchers' desire to take on organisational responsibility. Maguire's experience parallels mine in that co-researchers became increasingly confident in taking decisions and action during this phase, but still did not express a desire to take on much

responsibility (although they were proactive in discussing the social services correspondence at a centre users' meeting). I tended to take on the role of 'behind the scenes' organiser and administrator, for example drafting letters at the request of co-researchers. It is possible that co-researchers would have participated more in such organisational activities had I pushed them to do so. However, I was very conscious of other demands in their lives (particularly following periods of feeling unwell and personal difficulties for several of the group during this phase) and was fearful of putting pressure on co-researchers by asking them to take on responsibility for which they had not expressed any interest.

I did ask co-researchers to administer the questionnaire survey with other centre users, but although Sheila and Mike (the only two co-researchers present at that session) wanted the survey to take place they did not want to administer it themselves, and Sue and I were left to approach centre users to complete the questionnaires. We had a brief period in which to undertake some analysis of these questionnaires, and Mike and Sheila were interested to read the questionnaires and to note the number of people who stated that they also had difficulty in reaching the drop-in centre. As we only had limited time, we agreed that I would compile the results of the survey into a report, which co-researchers could then use if someone from social services came to talk to the centre users' meeting.

Overall, relatively high levels of participation took place in the decision-making processes and action-focused activities involved in this phase, with less enthusiasm amongst co-researchers for undertaking organisational tasks themselves.

New role for 'external' researcher

As highlighted above, I continued to provide organisational and administrative support and some structure to the group's sessions while encouraging them to take responsibility for making decisions and initiating action.

Nonetheless, there were occasions (particularly when attendance was low) where I felt that I had given my views too much, sometimes because I felt strongly about issues and at other times because I was attempting to 'keep meetings going'. This demonstrates the ongoing anxiety I felt about needing to work through the PR structure to satisfy the requirements of my studies, and the difficulties that can be experienced by researchers attempting to undertake PR and meet other (academic) agendas. Nonetheless, it was an interesting experience to be able to react 'naturally' to issues raised by co-researchers in a way that would not be considered acceptable in 'traditional' research (although I did attempt to avoid leading co-researchers by expressing very strong opinions).

With regard to participatory researchers demonstrating commitment to the project rather than detachment from it (David, 2002; Reason, 1998), I was very much involved in the group's action on transport and supported them in moving this action forward.

Empowerment processes and power relations

This section critically analyses the extent to which empowerment processes were occurring during this phase both for individuals and for the group. The complex power dynamics operating between all those involved are also explored.

Individual participation and empowerment processes

Attendance and participation levels again varied during this phase. At early sessions, some co-researchers were absent as they were feeling unwell, and those that were present seemed tired and subdued. However, as action began to occur and more co-researchers started to attend sessions, enthusiasm and participation levels increased

(particularly Amy, Mike and Sheila). At Session 21, for example, the group were angry about the social services letter, leading them to enthusiastically identify several valuable points to include in the response. They were very keen to challenge the social services department and to move forward with the group's work.

Towards the end of this phase, attendance declined once more and co-researchers who did attend seemed deflated. This phase again reminded me of the importance in PR of being flexible enough to respond to co-researchers' needs and circumstances. I felt that our work was probably less important than other events occurring in co-researchers' lives at the time and having an impact upon them.

A particular issue arose with Maria during this phase, as she decided to withdraw from the group. She stated that since the start time for sessions had been moved to 2:30pm, her time to participate in the group was too limited as she had to leave to get her taxi at 3pm. I was saddened by Maria's departure from the group, and felt that I might have partly contributed to this situation by not giving enough attention to her individually during the group work process. It was unclear to me whether participating in the PR group had been an empowering experience for Maria, and I hoped to be able to explore reasons for this withdrawal, and her perceptions of the PR process, via an evaluation interview.

Nonetheless, processes of individual empowerment could be seen to be operating for most of the remaining co-researchers. During this phase, co-researchers developed more confidence and an enhanced sense of the value of their voices. The group's determination to enter into correspondence with the social services department about transport demonstrated their desire to fight for what they wanted and to challenge professional interpretations of people's needs and circumstances. Session 22, for example, ended with co-researchers showing their determination to challenge social services and to be heard by them:

Rose We can tell them what we think when they come...

Sheila Now they don't think we're not supported, that we're just a voice in the wilderness.

Amy We've got them on a hot seat, anyway!

Similarly, at Session 22 when they were taking action on transport, an enhanced sense of confidence and personal power was evident amongst co-researchers. Their clear assertion of their right to good quality services and of their personal needs could be seen as elements of both individual and group empowerment processes (see p.201), as they attempted to influence the way in which their needs were met via joint action.

Sue spoke very positively about what she perceived to be improvements in co-researchers' confidence resulting from their involvement in the project, giving the example of the recently held Project Advisory Group meeting at which co-researchers had confidently and assertively raised the issue of transport, surprising professionals present. Another illustration that Sue gave in a conversation outside group sessions (which I noted in my journal) was of Mike's interaction with professionals at a recent case conference:

> Sue said that Mike never used to talk in his case conferences, and at his most recent one he kept saying how poor the services were and how his CPN hardly came to see him, in front of her, so he was definitely being more assertive... (Reflexive journal, 18th January 1999)

Another element of individual empowerment processes has been identified as enhancing skills and abilities. During this phase, some of the co-researchers developed their lobbying skills, by interpreting and responding to correspondence, and their research skills, for example by developing the survey questionnaire and interpreting its results.

Group empowerment processes

Processes of group empowerment identified in the literature (see p.201) were clearly operating during this phase, with co-researchers enthusiastically participating in joint action to secure improvements in resource allocation. During this phase, co-researchers

were working very well together as a group and appeared to be united in their determination to achieve change both for themselves and for other service users.

As well as taking action as a group, co-researchers expressed a desire to draw in other people to this action, a potentially empowering process for the group in itself. I hoped that their desire to involve other service users might help to integrate the PR group's work with other activities in the centre, thereby making their action more sustainable and potentially involving other service users in empowering processes.

Operation of power dynamics

Between co-researchers

The main issue of concern during this phase was Rose and Sheila's tendency to become impatient with Maria when she was talking, and the possible contribution of this power dynamic to Maria's decision to withdraw from the group. As two of the more vocal co-researchers, Rose and Sheila did exercise power over other co-researchers, not always in a productive way (as their attitude to Maria demonstrated).

Between research student and co-researchers

Both Sue and I made considerable input at the early sessions of this phase, as there was only one co-researcher present at each. Sensing the potential for loss of momentum at these sessions, we played encouraging roles, highlighting what had already been achieved and the positive action that the group was taking in relation to transport. In sessions where co-researchers were enthusiastically taking action, I took far more of a background role, merely giving some structure to the session. My feeling of a need to be directive and exert some power in group sessions therefore varied according to the size of the group and the level of their engagement with each session.

I was disappointed that Sue and I were left to administer the transport survey questionnaire, as I had hoped that co-researchers would participate more in this process. An alternative approach might have been to insist that if co-researchers wished to undertake the survey they should do so themselves, but this would appear to go against PR's ethos of attempting to reverse power relations so that researchers place their skills at the disposal of co-researchers as 'tools' for them to use for their benefit (Dockery, 2000).

Rose gave me a Christmas present at the eighteenth session, which I accepted with thanks. Although I was very conscious of the strong boundaries which the host organisation's workers maintained between themselves and service users, I did not perceive myself to be occupying the same role as them as I was not providing a service to co-researchers in the same way[155]. The professional 'distance' maintained by the project worker from service users appeared to create a different power dynamic between Sue and the co-researchers compared with the more relaxed and friendly relationship between myself and co-researchers (as witnessed by Rose's desire to give me a present).

During this phase, I also had to introduce the idea that I would need to withdraw from the project in April. I was aware that my imminent withdrawal would affect the power dynamic between myself and the co-researchers, as they began to realise that I would no longer be visiting them every week to support them in this work. I was also conscious that I was exercising power quite strongly by imposing an ending on the group in this way (due to my need to commence analysing data for this dissertation). Following the news that the host organisation definitely required the group to have ended by April (see p.296), I reflected that this did not necessarily coincide with the needs and wishes of co-researchers, who were still enthusiastically taking action.

---

[155] I did recognise, however, the structural power imbalances inherent between the co-researchers and myself, as a university research student and employee.

This reflects Wilding's (1982) identification of the way in which professional power can allow professionals to impose their needs and wishes on those of service users (see p.63-64). To attempt to mitigate this imposition to some extent, I told co-researchers that I would still like to visit them at the drop-in centre and that I hoped that issues raised by the group could still be worked upon through the centre users' meeting.

I was also conscious that I would be imposing individual evaluation interviews upon co-researchers for my benefit rather than theirs. I noted in my journal that "I think some of them get quite anxious about the prospect of being 'put on the spot', so I'll have to handle it very sensitively and make it as informal as possible" (Reflexive journal, 26th January 1999).

Between project worker and co-researchers

Power dynamics were clearly operating between the project worker and co-researchers in this phase, in that Sue was being pressurised by her manager to move on from the group to undertake another project. I felt that this pressure was emerging in the group, for example when Sue was emphatic in the review session that the group needed a reason to continue. While this was partly due to her concerns that the group might become a 'safe' activity for co-researchers, I also felt that it was partly due to this organisational pressure.

Nonetheless, co-researchers did not yield to this pressure from Sue, clearly stating that they wished to continue working in the PR group, and demonstrating confidence in making decisions that did not necessarily agree with Sue's wishes.

At the end of Session 22, Sue informed me that she was under instructions from her manager to end our group in April and move on to running a gardening project. Like me, she recognised that the group was being asked to end when co-researchers were carrying out some very valuable work. I asked whether there was tension between the group and the host organisation manager, but Sue felt that the request was purely because the centre did not have enough staff to carry out all the work that needed to be

done. We therefore agreed that if the group had to finish while activities were still outstanding, Sue would attempt to incorporate these activities into the weekly centre users' meetings at the drop-in centre.

The host organisation manager also asked Sue to invite co-researchers to attend another PAG meeting to raise the transport issue once more. Sue commented that Rose and Sheila had raised this issue at the last PAG meeting, and that this was far more effective coming from service users than from host organisation staff. However, none of the co-researchers responded to this request and did not seem keen to attend. I observed in my journal that:

> I think they find the prospect of planning to be a spokesperson at a meeting quite daunting, even though they do tend to be happy to speak at meetings... we can't make them do things in the way that we would like them to, we have to let them take the initiative. (Reflexive journal, 22nd February 1999)

It was important to recognise that while the host organisation's efforts to encourage co-researchers to take part in 'user involvement' opportunities arising were a positive development and provided recognition of the work that co-researchers were undertaking, it could not be assumed that co-researchers would want to participate in these professionally-defined activities, particularly if they did not perceive any benefits from them.

Between research student and host organisation

At Session 18, Sue introduced a survey questionnaire for service users received from the host organisation's national office on the Mental Health Act Review, which the host organisation manager had suggested the PR group might be interested in completing. I was pleased that the manager had made this request as I felt that she was viewing us as a research group.

With regard to the group's correspondence with social services, Sue asked me to write to a more senior manager in the host organisation with details of our project and copies of this correspondence in case social services approached this manager about the issue. This request reminded me of the rather uneasy power dynamics that continued to exist between myself and the host organisation manager, who appeared to be anxious about possible ramifications of our work (particularly our challenges to social services) for the host organisation's future security (as an organisation reliant upon its 'contract' with social services for funding) (Reading, 1994).

Unfortunately, the host organisation also exercised power during this phase to stop what would have been an important experience for co-researchers from occurring, namely interviewing a manager from the local psychiatric hospital. I had provisionally agreed the date of our penultimate session for this interview with the hospital manager, but was then informed by Sue that we could not hold the interview on that day as she was going on an outing with some of the service users, and was quite adamant that this interview could not take place without her. As the hospital manager was not available on any of the other dates available before the end of our project, I was forced to cancel this interview, which was very disappointing.

In relation to the host organisation manager's 'directive' to end the PR group, I felt that while in theory the group was independent of that organisation to a certain extent and could therefore have continued to meet, in reality we relied upon the support and space provided by the host organisation. As this request coincided with the time when I needed to withdraw from the group, I yielded to this exercise of power by the host organisation. However, if this had occurred earlier in the PR process, I might have attempted to continue with the group if co-researchers had expressed a desire to do so.

Between co-researchers and social services staff

Co-researchers made strong challenges to the authority of social services senior management during this phase via their letters to the councillor and senior manager, demonstrating 'resistance' (Foucault, 1980) to the professional power being exercised by social services by defining how they thought services and transport arrangements should function. Co-researchers were confident to present their own, alternative conceptualisations of the situation, and to assert their needs and wishes to this statutory organisation.

Nonetheless, the way in which such an organisation could exercise power over service users even 'at a distance' was clear in co-researchers' reaction to the senior manager's reference in her letter to the need for constant monitoring and evaluation of the day service provided. This led to anxious questions from Sheila about whether they were constantly being reassessed (as highlighted on p.58 in relation to disciplinary power), although I explained that this referred to assessment of the service being provided rather than of the service users.

After the positive response and support we had received from the councillor who had been interviewed by the group, I was unhappy at the way in which social services staff had treated the co-researchers on this issue, for example their use of condescending phrases and professional jargon in their correspondence, and their dismissal of service users' concerns at the PAG meeting. Such strategies are clear examples of the way in which professionals directly exercise power over service users (Hugman, 1991) to maintain them in their position of structural inequality in relation to organisations (Thompson, 1998; Wilding, 1982). Social services' expressed commitment to 'user involvement' did not appear to translate into practice when faced with these challenges from co-researchers.

Conclusion

Maguire (1987) gives the following description of Phase Five of PR:

> ...researchers and participants decide on what actions to take to address the problems that they have collectively defined and investigated. In this way, both the process and products of research can be of direct and immediate benefit to those involved. (p.42)

This description applied to our project in that we worked together to define action and to start to take action on transport. The extent to which this action was of 'direct and immediate benefit' was however questionable, in that the outcome desired by the group (that of free taxis) was not forthcoming during this phase. It is important to note, however, that Maguire entitled this phase *definition* of action projects, acknowledging that any action may take time to yield results.

This was a very positive phase of our project, in which co-researchers confidently challenged social services on transport, drew in other centre users to this debate, thoughtfully analysed and interpreted correspondence, sought to influence local policy and practice on transport to day facilities and on the nature of those day facilities themselves, and carried out a survey to provide additional information to reinforce these challenges.

Many of these activities have been identified as strategies for empowerment for mental health service users (see p.173). The successful action that co-researchers took could therefore be seen to have contributed to individual empowerment via the knowledge, skills and confidence gained through activism, and collective empowerment via a stronger sense of entitlement and power to influence conditions amongst co-researchers and possibly other centre users.

Similar to Maguire's findings, the research and action elements of our project overlapped in reality and it was not possible to categorise activities too rigidly, reinforcing the finding in the previous chapter that co-researchers were likely to choose to move forwards and backwards between defined PR phases.

Attendance at group sessions during this phase varied considerably, with some sessions attended by very small numbers while others were attended by all co-researchers. I was struck that every co-researcher had a period of feeling unwell (either physically or mentally) during this phase, and concluded that researchers involved in PR should strive to work flexibly to incorporate these fluctuations. Nonetheless, processes of both individual and group empowerment were continuing to operate during this phase, particularly as co-researchers confidently engaged in joint action to achieve change.

Contradictory power relations were occurring with the host organisation in this phase, with the organisation supporting and encouraging the group's work on one hand yet placing pressure on Sue to end this work before its 'natural end' on the other. I concluded from these experiences that such power relations were in all likelihood unavoidable when undertaking research in a setting involving a 'gate-keeping' organisation, although they could be reduced by maintaining clear boundaries between the research group and the organisation and by providing full information to the organisation on the group's purpose and its activities.

Nonetheless, a positive aspect of a host organisation's involvement in such research was the potential for some of the action taken by the group to be continued via the host organisation, rather than finishing with the end of the time-limited project, and possibly strengthened if other service users became involved.

I aimed to encourage this integration of the group's work with that of the host organisation by continuing some contact with host organisation staff and co-researchers. I also identified a need to spend some time with co-researchers both collectively and

individually, to explore their views on involvement in the group and on the group process itself. This exploration forms the basis of the next chapter.

Chapter Ten: Ending the Research

Introduction

As discussed earlier (p.184-185), it is important to give attention to the 'ending' of a longitudinal research project such as that undertaken in PR (Northway, 1998). This ending process is identified as a sixth phase of PR in this dissertation, and is reported in this chapter.

The first section describes the last group session held, at which attempts to undertake group evaluation of the PR project were only partially successful due to low attendance. Empowerment processes and power dynamics operating at this session are explored. Individual evaluation interviews were also held, both with co-researchers and with the project worker, and findings of these interviews are presented in the second and third sections of this chapter. The final section documents my ongoing contacts with the co-researchers and host organisation, highlighting action arising from our PR project, continuing empowerment processes, and my relationship with the host organisation.

Ending the group

Content of session

The final group session took place on 23rd March 1999. Unfortunately, only two co-researchers, Rose and David, were present with Sue and myself[156], and the meeting was relatively short[157].

---

[156] Both Amy and Sheila were feeling unwell, and Mike was away at a respite care centre.
[157] Rose and David had to leave to get the council subsidised transport after half an hour.

We talked about what had been achieved by the group. For example, Sue reported that the council's Income Maximisation Unit had agreed to hold individual appointments with service users at the drop-in centre, which she felt was a direct result of the group's work. We also talked about ongoing activities (such as disseminating the transport survey results and liaising with social services) and how these might be taken forward via centre users' meetings. I asked co-researchers present for their permission to interview them individually about the group's work, and talked about how we might stay in contact beyond the end of the group.

Rose stated that she would like the group's work to continue in some form. I noted that although I would not be working with the group any more, I would still like to keep in contact by visiting the centre and attending sessions if the visitors with whom we had initiated contact did come to centre users' meetings. Sue and I emphasised that the work in which the group had been involved did not have to finish when the group ended, as co-researchers could continue to raise issues via the host organisation, its users' meetings and the PAG. I ended the session by thanking co-researchers for participating in the project, giving out individual thank-you cards and cakes.

Throughout these exchanges, Rose kept returning to talk about her experiences, both of living with mental distress and of care in the local psychiatric hospital, demonstrating her ongoing desire to share these experiences in a safe environment.

Participation and empowerment processes

This session was rather subdued, partly as only two co-researchers were present but also because Rose was feeling unwell. She was therefore less talkative and assertive than usual, and found it difficult to focus.

Nonetheless, we spent some time talking about co-researchers' views of their participation in the group. Rose stated that she had enjoyed the group and felt that they had "accomplished a lot", identifying joint action taken by the group as important. She

felt that it was now vital to see whether interviewees acted upon any of the issues raised by the group, demonstrating a desire to see material benefits emerging as a result of the group's work. David found it harder to talk about his experience of the group as he had joined at a later stage, but stated that he had found the interviews with professionals interesting[158].

Operation of power dynamics

Between research student, project worker and co-researchers

Both Sue and myself tried to create a feeling of celebration at this session, emphasising how much the group had achieved and how this work might be carried forward via other work in the host organisation. However, this was difficult as the co-researchers present were very quiet. I left this session with a feeling that the group's ending had been an 'anti-climax' for all involved, after the vigour and enthusiasm of previous sessions.

Between research student and host organisation

Sue seemed keen to carry forward the group's work via host organisation activities, which I felt was a positive outcome. I was unsure, however, whether activities such as instigating more interviews would occur without someone specifically driving that work.

PR methodological principles in practice

It was regrettable that only two co-researchers were present, as I had hoped to thank the group as a whole, and reflect with the group together on their involvement in the project to mark its ending. I reflected in my journal that this disappointment was part of the reality of undertaking research with a group of people with other pressures in their lives. If the host organisation had not identified the need to end the group on this date, I might have attempted to hold another session and encourage all co-researchers to attend to celebrate their achievements, but this was not possible.

---

[158] I tried to ask co-researchers further questions about being involved in the PR process at this session, but this proved difficult as Rose was feeling unwell.

My attempts at carrying out some evaluation as a group were therefore of only limited success, largely due to how the two co-researchers present were feeling. I felt that it might be more effective to ask them questions individually, and therefore looked forward to the individual evaluation interviews for this purpose. Findings from these interviews are reported in the next section.

Evaluating PR: individual interviews with co-researchers

Background to interviews

Interviews with co-researchers were held on 4th and 11th May 1999. The interviews were quite brief, but generally went well. At the beginning of each interview, I again negotiated consent with co-researchers to use information and quotations from our interviews and discussions in an anonymous form in my dissertation and other publications. I used a semi-structured interview schedule (Appendix 3) with co-researchers[159], and tape recorded the interviews for transcription.

Individual participation in interviews

All of the co-researchers (with the exception of Amy) appeared to be nervous about being asked questions in a one-to-one situation. I felt that this nervousness might have been partly related to their experiences of being 'interviewed' or 'assessed' by professionals in this way, leading me to question whether interviewing them individually was the most effective way to obtain feedback from them. Nonetheless, as group evaluation had not been possible to any great extent, it was important for this doctoral work to obtain some evaluative data from co-researchers.

---

[159] I did not ask the same questions of all co-researchers, as some of the questions were quite similar and some co-researchers were considerably more responsive than others in these interviews, so I was sensitive to these differences.

With regard to individual co-researchers, Rose was not feeling well when we talked but was still able to participate in the interview. Amy was the least nervous and most forthcoming in her interview. Although Sheila was initially quite talkative in her interview, she changed halfway through and started to give very brief answers. Mike appeared to find it hard to express himself in this situation. He found it difficult to elaborate upon his answers, and kept repeating himself. David noted that it was difficult for him to reflect on the whole project as he had missed the initial sessions, and also appeared to be nervous in this interview situation.

I attempted to interview Maria, but she did not seem well so I ended the interview soon after starting. Her comments quickly led me to feel that she was becoming unwell and therefore attempting to interview her felt inappropriate. When I talked to Sue after this incident, she confirmed that when Maria started to make such comments this was a sign that she was experiencing symptoms of mental distress. The interview findings presented here do not therefore include comments made by Maria, which was unfortunate as I had hoped to gain some insight from her regarding both her reasons for withdrawing from the group, and whether she felt that she had benefited in any way from participating in PR.

Findings

This section presents findings from these interviews thematically, with regard to individual and group empowerment processes, the wider impact of the PR project, continuing the group's work, and PR methodology and process issues.

Individual empowerment processes

The operational definition of individual empowerment processes used in this dissertation is highlighted on p.201. Although I consciously chose not to use this definition when questioning co-researchers, it was clear from their answers to my more general questions

about potential benefits from participating in the PR project that the experience had enabled some of the co-researchers to engage in processes of individual empowerment.

All five co-researchers interviewed felt that they had benefited from taking part in the group. Some felt that these benefits related to taking action to improve their situation, while others cited sharing experiences and gaining information as beneficial for them. Personal benefits in terms of increased confidence to speak out were also mentioned:

> I've benefited through being able to change things, being able to get things done. (Rose)
>
> It's improved my confidence, and a way of fighting to get what you want and for other people who find it difficult, to improve things in certain services... It's made it easier to get your opinion across... It's helped me speak out rather than hold these feelings in and go about it totally the wrong way. It's helped me deal with issues. (Amy)
>
> I've been able to talk to people about the problems we have... And the people didn't really look down on you like they do... 'Cos sometimes you feel they look down on you, at the care meetings... (Sheila)

The differences in emphasis given to activities by co-researchers were reflected in their responses to a question about what they felt to be the group's main purpose. While Rose viewed this as "getting involved in things and to get things changed", and Mike cited "getting people along to interview them", Sheila identified the group's primary purpose as "the other people talking about their experiences". Participation in groups has been identified as important in processes of individual empowerment (Lee, 2001), and the mutual support and sharing of experiences within the PR group appeared to have contributed to individual empowerment processes for some co-researchers.

David stated that the group's main aim for him had been "to gain information about various things of our illness", while Amy identified its primary purpose as:

> Getting your voice across, being heard and being acknowledged that 'Yes I am a person and yes I do find it difficult for certain issues'... Talking to people that have come out, like the nurses and things like that has been really great... It's nice to actually ask them questions and find out for yourself. (Amy)

Having her voice heard and acknowledged therefore appeared to be an empowering experience for Amy.

Co-researchers felt that they had learned from being in the group, and again their individual learning related to their personal needs. Sheila stated that she had learned "to express yourself", while Amy commented that "it's made me realise how the system works and how people work in it". Both Mike and David felt they had learned from the information shared in the group and obtained from the interviewees.

Segal et al (1995) suggest that individual empowerment operates at personal, organisational and extra-organisational levels. For some of the co-researchers, their comments suggest that individual empowerment occurred at a personal level, in terms of increased confidence and self-esteem, and at an organisational level in their willingness to voice opinions and attempt to influence procedures within the host organisation. The third level identified here appears to be a more long-term goal, and one which I feel might have occurred for some co-researchers had the project continued for longer.

Group empowerment processes

The operational definition of group empowerment processes (given on p.201) could also be identified from co-researchers' comments. As highlighted above, sharing experiences was identified by co-researchers as a benefit of participating in the group, as was conducting interviews and taking joint action. Co-researchers expressed a strong sense of the group working together to achieve change, using their collective voice and influence.

All five co-researchers interviewed identified group achievements. Rose, Amy and Sheila commented on how pleased they were that they had been able to lobby successfully for a subsidised transport scheme for centre users (see p.314). Rose and Amy also felt that the interviews with professionals had been an achievement for the

group, in that "we got a lot of people in and told them what we thought, and they've listened to us" (Rose).

Wider impact of the PR project

All co-researchers felt that their work in the PR group had had some impact on the host organisation. Rose mentioned the benefits that the subsidised transport scheme would bring to all centre users, stating "we've done that for everybody". Mike felt that the group's work "trickled down to them... talking to people informally and the members' meetings".

Similarly, Amy felt that the PR group had contributed to an increased sense of confidence amongst centre users as a whole: "there seems more sort of like a fighting spirit... they're a bit firmer in their own minds about what they want and how to go about it". Three co-researchers also expressed contentment at having worked to improve conditions not just for themselves but for everyone at the centre, demonstrating their sense that the PR group had contributed to improvements in a wider context. David also felt that the experience of working with the group would enhance Sue's skills.

Continuing the work of the PR group

All five co-researchers hoped that the work of the PR group would continue in some form via the host organisation (possibly its centre users' meetings), identifying the importance of work undertaken in such a discrete project being integrated into a wider forum and drawing in more people:

> ...'cos it's like a prop, isn't it?... If they have... issues that they want to discuss, at least they approach somebody and they can all band together and try and get them some answers... rather than just sit there. (Amy)

Amy therefore clearly identified such group work as beneficial for people both in providing them with an opportunity to share their experiences and problems, and to work together to find solutions.

PR methodology and process issues

An important element of this research was to consider the extent to which PR methodological principles could be implemented in practice with a group of people using mental health services, to further develop methodology in this field. The interviews therefore included questions about the processes implemented in the PR group. However, co-researchers had very little to say about these processes[160]. Nonetheless, their responses to my questions on process are outlined below.

When asked whether they would have liked to have undertaken any additional activities, four co-researchers stated that the group had covered everything that they had wanted to. However, Amy felt that it would have been valuable to obtain more information on the local psychiatric hospital, as it was an issue that had been raised many times by co-researchers.

I also asked co-researchers whether there was anything they did not like about being in the group. None of the co-researchers identified any factors in response to this question. David commented that "I think everybody was open with one another and shared their experiences" while Amy felt that "tackling the issues was a challenge to me".

Similarly, co-researchers felt that nothing could have been done differently to make the group a better experience for them. Nonetheless, Sheila mentioned the size of the group, stating "perhaps we could have had more people, because we were a very small group". This sentiment was echoed by Mike, who felt that the group worked better when more people were present. These comments therefore suggest the need for PR groups to have at least a few more members than was the case in our project, particularly if co-researchers are likely to have periods when they are unable to attend.

---

[160] I was uncertain whether this lack of comment was because co-researchers were conscious of the work I had done and did not want to 'upset' me, or because they did not necessarily perceive a process as such and therefore did not have views on how it could be changed.

With regard to the group session format, based on discussion backed up with written information, all co-researchers felt that this was the most appropriate format at the time. Three felt that they could not see how it could be done differently, as "we had to talk and discuss it all" (Mike). Amy related her response to the stage that she felt co-researchers had reached in their process of personal development at the time of the group sessions, and suggested that co-researchers were now more confident to organise activities themselves (implying that empowerment processes had occurred as a result of involvement in the group):

> ...there was a lot of people who found it quite hard to talk, so to do something else might've taken that away... I feel talking was enough yeah, for the people at the time that were in the group... obviously their confidence is a bit higher now, so maybe for those people they could do something at the next step ahead, like do a little survey of their own... (Amy)

Amy suggested that for people who found talking difficult, an alternative approach might have been for them to write down their feelings and for this to be fed back into the group anonymously as a basis for discussion.

Amy also commented on how valuable she found the sharing of written information in the group, validating this approach to sharing knowledge in PR:

> Everything we spoke about was written in confidence back to us, so we knew what was being said... 'cos obviously when you fall ill, sometimes it's quite easy to forget what you've said... so it's handy to go through the transcripts... and think 'Oh yeah, that's what it's about'. And maybe the things you've missed, you can sort of catch up on in your own time. (Amy)

All co-researchers felt regular weekly meetings were appropriate, with both Amy and David emphasising the importance of maintaining group continuity via frequent meetings:

> I think it was right to keep going every week, to follow it through... I think when you have a break, you lose contact a bit... (David)

Amy felt that it was particularly important to have weekly sessions in the early stages of such a project, when people tended to be less confident and comfortable with one another, and that as the project progressed sessions could then become less frequent.

Finally, I asked co-researchers whether they felt that meeting for a year was an appropriate length of time for such a project. Rose and Mike felt that one year was appropriate, with Rose commenting "there's not a lot more we could have covered". In contrast, Amy and Sheila stated that they would have liked the group to continue as they had enjoyed it so much, although Sheila also acknowledged that "I don't think there's much else we could talk about". David felt that it was not necessarily important to set a time limit on a group, stating that "as long as you had something to talk about, it doesn't matter how long it goes on... you're getting something out of it". It therefore appeared that the project's length was less important to co-researchers than maintaining a sense of purpose to such work, suggesting that PR should ideally form part of a long-term programme of participatory work and action for change.

Power dynamics between research student and host organisation

After the interviews, I spent some time in the drop-in centre chatting and doing activities with co-researchers. Most of the group asked whether they would still see me. I said to Sue that I would like to return to the centre on occasion for lunch, but she was not very enthusiastic about this suggestion and said that she would have to ask other users. I felt that this reticence might have been due to her desire to ensure that co-researchers could see that the group had definitely ended, and noted that this gate-keeping role played by the host organisation was one which I could do little to overcome. I noted in my journal that I was sad to be ending the group, but pleased to see that the host organisation's work was providing opportunities for co-researchers to be involved in decision-making.

Evaluating PR: interview with the project worker

Background to interview

I interviewed Sue on 28th April 1999, approximately one month after the end of the group. Sue was keen to tell me good news about the transport issue. She informed me that the group's report on the transport survey (Appendix 12) had been passed on to the host organisation's social services link officer, who had identified some available funding and asked the host organisation to put together a proposal for a transport scheme for centre users. The link officer stated that this would be viewed as a pilot scheme that could be extended to other drop-in centres run by the host organisation across the city. Rose, Amy and Sheila had contributed ideas for the transport scheme, and Sue had then drafted a proposal for social services. I felt that this was "a breakthrough, and concrete action from the research" (Reflexive journal, 30th April 1999).

Sue also gave me a thank-you card organised, purchased and signed by all co-researchers. We then moved on to the interview, which I conducted using a semi-structured interview schedule (Appendix 4) and tape recorded for transcription.

Findings

The findings of this interview are again presented thematically, mirroring the structure of the previous section.

Individual empowerment processes

I asked Sue about her perception of whether each co-researcher benefited from being in the group, and the nature of those benefits (again avoiding using leading language in relation to empowerment processes). Sue's comments on each co-researcher are highlighted in Table 17.

Table 17: Project worker's perceptions of benefits of PR project for individual co-researchers

Name	Project worker's view of extent and nature of benefits
Rose & Sheila[161]	• Improved their confidence "because they don't let things drop now and they're far more happy to be vocal about the things they're not happy with." • Sheila used to complain to other centre users about issues and not take any action herself but was now "taking a more active role" on issues. • Good for Rose and Sheila to be involved in lobbying and decision-making "because it made it much clearer what those processes are, instead of this big thing that goes on behind closed doors."
Amy	• Confidence-building and empowering experience for her, despite not feeling well and not being able to attend consistently. • "She's somebody who's always been quite happy to talk about what the problems are but not quite clear where to follow through and now she's got an idea of the structures that we can use and stuff, so that's confidence". • Amy found transcripts very useful to catch up with missed sessions.
Mike	• Boosted his confidence and gave him skills and language to put across his views. • Since being involved, Mike had been vocal at discharge and care planning meetings in asserting his needs and criticising services. • Mike had also volunteered to give his views at a consultation meeting: "he's very clear that that's what he wants to do, to carry on that role that he's had in the group."
Maria	• Group was a difficult experience for Maria at times because of Rose and Sheila's impatience towards her: Sue believed that this had contributed to her decision to leave the group in its later stages. • The GP interview had been a very positive experience for Maria: "the best one for her… was when (the GP) involved her and then it became crystal clear how much she understood about things… and what she thought about things, and I think she got a lot out of that."
David	• More difficult for David as he joined later and so missed out on sharing experiences with co-researchers. • Nonetheless, David enjoyed being involved: "I think he liked the space to come away and be involved in something different and have his say about things or be involved in those interviews. I think he got quite a lot out of that."

It can be seen that, similar to the co-researchers themselves, Sue identified the operation of a range of empowerment processes for individual co-researchers, including improving confidence and self-esteem, obtaining information, using their voices to express their needs, and enhancing their skills.

I also asked Sue whether she felt that being in the group had entailed any negative or unexpected effects for co-researchers (in acknowledgement of the potentially disempowering experiences that might also occur when involved in such work). She referred to the disappointment felt by some co-researchers, and expressed to her, that they had not obtained results on transport during the project's existence, despite all their hard work. Nevertheless, Sue felt that it was important to emphasise that the co-researchers had achieved a lot, for example carrying out the transport survey, which they were very proud of, and achieving support and help in relation to benefits.

Group empowerment processes

Sue identified the sharing of experiences, and joint action undertaken by co-researchers to obtain improvements in resource allocation and service configuration, as important achievements of the group. Both of these processes have been identified as group empowerment processes (see p.201).

Participation in PR

When I asked Sue whether there were any particular factors that she felt had facilitated co-researchers' participation in the project, she referred to the encouragement given to co-researchers by herself and by me, and to the work which I had put into organising the project. She also felt that co-researchers' interest and motivation was facilitative, as was having a specific issue to work on. The use of space away from the host organisation's building for sessions, and the fact that it had been a closed group (thereby maintaining continuity in membership and discussion), were also identified by Sue as helpful.

With regard to factors that she felt had made co-researchers' participation in the project more difficult, Sue identified language difficulties for Maria, people's changing levels of mental distress (particularly for Amy and David), and an element of rivalry between Rose and Sheila (illustrated by instances of Rose encouraging people to collude with her against Sheila when she was not present).

---

[161] Sue talked about Rose and Sheila together as she felt that they had obtained similar benefits from participating in the group.

Process issues

Sue felt that the approach that I had used to recruit people into the research project, namely bringing the proposal to service users and letting them decide whether they wanted to access the group, was very appropriate. However, Sue reinforced my concerns about the tension at the start of a PR project (between giving potential co-researchers some guidance and structure and leading them too much with regard to research topics) by highlighting some initial confusion and curiosity over exactly what would be involved in taking part. Nonetheless, she felt that this uncertainty was quickly dispelled once co-researchers began to work together and share their experiences.

I asked Sue how she felt each phase of the group process had progressed. She thought that the phase of talking about and sharing experiences (Phases Two and Three of PR) went well, with people becoming involved in this quickly and gaining a lot of personal benefit from it. The fourth phase, of researching issues via interviews, was one which Sue identified as having been more successful than she had originally expected. With regard to the fifth phase, of action based on the interview findings, Sue felt that the group did want to take action but tended to depend on me to drive this forward, possibly due to the co-researchers' limited experience of being given opportunities to take control:

> I think they wanted to do something about it but didn't want the hassle of doing it themselves, so they lent quite heavily on you, and I think if we'd run that group for a bit longer... maybe we could have pushed it back to them a bit, because it was starting to get there... they *were* gaining in confidence... (Sue)

I asked Sue whether there was anything that she felt could have been done differently to help the group run more effectively, but she did not identify any ways in which she felt this could have been improved.

With regard to possible ways we could have increased attendance at group sessions, Sue identified the need to put such an issue back to co-researchers to encourage them to be

explicit about their reasons for non-attendance and to take some joint responsibility for maintaining momentum. However, she also acknowledged the host organisation's gate-keeping role, which made it harder for me to check with people about their attendance. On the whole, Sue felt that it was transport problems and periods of feeling unwell that affected people's attendance at sessions.

Wider impact of the PR project

In terms of the PR group's possible impact on other drop-in centre users, Sue stated that the group's work had been reflected in centre users' meetings, as co-researchers had talked to other centre users and had encouraged them to become involved in action. She also felt that the group's work was contributing to the host organisation's ongoing work to encourage people to have a say.

Sue acknowledged that the new host organisation manager had initially been unclear about what the PR group was doing and for what purpose, but as she learned more about the group from Sue and co-researchers she recognised the importance of the group and its achievements.

Continuing the work of the PR group

Sue hoped that the work of the group would continue, and identified the proposal that had been submitted to social services for a subsidised transport scheme (to which co-researchers had contributed) as an example of this already happening. Sue also highlighted the links that had been made with the Income Maximisation Unit and the valuable benefits advice service that they were providing to all centre users.

Further developments and ongoing contact with co-researchers and host organisation

After these evaluation interviews, I maintained contact with Sue and was invited to several social events held by the host organisation. My experiences at these events, and during subsequent contact with the host organisation, are documented in this section to demonstrate ways in which our PR group's work continued to influence both co-researchers and others within the wider service context.

Summer 1999

I was invited to the host organisation's summer fair in July, at which I saw Rose, Sheila, Mike and David. I was very pleased to see co-researchers again and spent time talking to all of them. The first thing that Sheila said to me was "I like it much better here now, I'm much happier". She also seemed very optimistic that the taxi scheme would come to fruition.

Sue updated me on the taxi situation. The host organisation had submitted a proposal to social services for a subsidised taxi scheme (Appendix 13) and was then asked to provide more supporting information (Appendix 14), so Sue was hopeful that it would be funded. A very positive aspect of this process was that Sheila had volunteered to be co-ordinator of the taxi scheme, collecting money and keeping track of people's use of the service. Sue felt that this illustrated the considerable progress that Sheila had made in recent months, and it certainly demonstrated the continuation of empowerment processes for Sheila in terms of her increasing confidence, sense of personal power and more positive self-definition.

I was also invited to a barbecue in August, at which Rose, Sheila and Mike were present. I spent time talking to Rose and Sheila, both of whom seemed optimistic that the taxi service would be funded in time. The action element of our PR project was clearly still ongoing, with co-researchers continuing to lobby for improved transport. Rose also

commented several times that "we achieved a lot in our group", demonstrating her lasting sense that involvement in the group had been beneficial.

I also had a very positive conversation with the host organisation manager, who I felt was being far more supportive of the work that the PR group had initiated now that positive practical outcomes were apparent. I was pleased that she was driving forward the issue of subsidised transport, as I had hoped that the host organisation would take on board the group's work in this way. Project workers were also talking about arranging appointments for people with the Income Maximisation Unit while I was there, so again I was pleased that the PR group's work was helping to improve people's circumstances on an ongoing basis.

Autumn 1999

I received in the post from Sue copies of all the information about the taxi service, including a letter from social services agreeing to fund the service. When I telephoned Sue, she confirmed that the service had been running since the end of August and that it was being well used by people at the centre. She also confirmed that Sheila was working as the co-ordinator of the scheme, and that they were hoping to make this an 'official' position for her. Sue felt that this role was benefiting Sheila in many ways, and that Sheila had changed considerably. Sue commented that "whereas before she used to just sit and complain that there was nothing to do, now she's keen and enthusiastic and suggests activities and gets people doing things" (Reflexive journal, 22nd October 1999). This was clearly a very positive change in Sheila, which I was pleased to hear about and which I hoped was in some part due to the work that we had done together.

Later in the autumn, Sue obtained a new job as a development worker for a local mental health service user forum. I was very pleased that she had found the opportunity to use her skills and creativity in such a post, and hoped that her experience of working with our group had contributed to the development of these skills. However, as I feared, Sue's move to another organisation meant that I had far less contact with the host

organisation and therefore co-researchers from this point onwards. I was invited to attend the host organisation's Christmas party, at which I saw Rose, Sheila, Mike and David. However, further staffing changes meant that my contact with the host organisation was very limited throughout 2000.

Autumn 2000

In September 2000, I received a telephone message from Sue stating that co-researchers from the drop-in centre were trying to contact me via a new worker there. I phoned the drop-in centre and spoke to the manager, who said that our group wanted to start meeting again to review the taxi scheme and to look at what else they could do, and they hoped that I could facilitate those sessions. I was very pleased at this contact, and at the ongoing empowerment processes amongst co-researchers which it demonstrated, in that they were organising themselves to assert their needs and influence services.

I subsequently spoke to the new worker, who confirmed that people involved in the transport scheme wanted to meet with me again to review the scheme and to obtain support to implement changes. I gave him two possible dates when I could attend a meeting, making it clear that I would not be able to return and work with the group over a period of time (due to my work and study commitments) but would be happy to attend for one session to facilitate a discussion of their options.

However, the worker did not contact me again. Some months later, I wrote to the worker asking him to inform me of the outcome of the group's request to start meeting again. I then received a telephone call stating that as the group wanted someone to facilitate sessions over a period of time, they had found another independent facilitator to work with them. I was very pleased to hear that co-researchers were keen to put across their views and take action to achieve desired improvements in this way, thus building upon the work that we had undertaken together.

Conclusion

The 'formal' ending of our group was disappointing in that only two co-researchers were able to attend the final session, which meant that this represented a less 'complete' ending for co-researchers than I would have liked. However, I was conscious that co-researchers were not feeling well at the time, demonstrating the need for participatory researchers to be sensitive to the realities of people's lives and the constraints which these might place on their participation in a longitudinal research project of this nature.

The evaluation interviews, and the interview with Sue, showed that people felt that they had achieved successes in the project, in particular their work on transport, and also that they had gained benefits from participating. These benefits included increases in confidence, finding it easier to speak out, obtaining a better knowledge of systems, having the opportunity to share their experiences with people, being able to ask professionals questions and receive answers, and having a way of fighting for things, all of which can be identified as elements of individual empowerment processes (see p.201). Co-researchers also felt that they had achieved change for other people, not just for themselves.

Group empowerment processes of participating in joint action to achieve change, and collective consciousness-raising via sharing experiences, were also apparent in co-researchers' comments on their experiences.

It should be noted here, however, that individual and group empowerment are not necessarily linked. From our work, I would conclude that co-researchers engaged in group empowerment processes, but nonetheless not every co-researcher engaged in processes of individual empowerment. Maria, for example, clearly enjoyed the interview with the GP and was pleased to share her experiences with her, but it was not apparent that the experience had been empowering for her in the same way as it had been for other co-researchers.

Areas for methodological development of PR raised by co-researchers and Sue included observations that the group could have been bigger in order to maximise participation and progress, and that co-researchers could have taken on more responsibility for maintaining the group's activities themselves.

As I stayed in contact with co-researchers via social occasions, I was able to learn of any developments resulting from the work we had undertaken, such as the funding of the transport scheme. It was also very satisfying to learn that empowerment processes were still ongoing for co-researchers, for example Sheila developing the confidence to take on an official organisational role. However, maintaining contact became far more difficult when Sue left the host organisation and several further staff changes took place. This was disappointing for me, but reflected the reality both of organisational change and of people's changing lives and circumstances. Nonetheless, it was very encouraging to receive a request from the co-researchers to reconvene to look at other issues, even though I was unable to respond fully to this request due to other commitments. This request from co-researchers demonstrated that they perceived the PR process both to have been beneficial for them and to be a valuable way of exploring other issues. It also suggested that over time, co-researchers are likely to feel increasingly confident to lead such work themselves, with minimal organisational support.

I was conscious of and tried to be sensitive to the need for managing the ending of the group as positively as I could. I believe we achieved some success in this, partly as co-researchers continued to be supported by Sue and also as they developed in confidence to take forward issues without my support. I would therefore conclude that it is important to pay attention to the ending of PR projects as a vital part of the research process. Nonetheless, my ability to remain in contact with co-researchers was limited by the gate-keeping role played by the host organisation, as I did not hold any direct contact details for co-researchers, again demonstrating the constraints imposed on PR projects by the involvement of such an organisation.

The next chapter of this dissertation draws together the findings of this PR work (presented in Chapters Seven to Ten) and synthesises them with the theoretical and conceptual literature presented in earlier chapters to demonstrate how this work has met the aims of this doctoral research.

Chapter Eleven: Discussion

Introduction

This research aimed to: explore the nature of oppression and power in the lives of mental health service users in Britain; assess the extent to which participatory research might function as a strategy for empowerment for mental health service users; consider the extent to which PR principles could be adhered to in research with mental health service users; and highlight issues for methodological development arising from the practice of PR.

The potential of PR as a strategy for empowerment was explored via a year-long research project in which I worked jointly with a group of mental health service users as 'co-researchers', sharing their experiences, identifying problems they wished to research, undertaking this research, reflecting on findings and taking action.

This chapter critically analyses findings from this PR project, in light of the theoretical, conceptual and empirical literature reviewed in earlier chapters of this dissertation. Discussion is presented according to the four aims of the research identified above (with the third and fourth aims combined as the fourth flows from the third).

In addition, it is noted that Humphries et al (2000) identified important elements to include in analysis of social research with emancipatory potential (see p.156), which I have attempted to incorporate into the discussion and conclusions which flow from it (outlined in Chapter Twelve).

The nature of oppression and power in the lives of mental health service users

We did not use the analytical discourse of oppression and power (presented in Chapter Two) to discuss people's experiences during our PR project. Co-researchers did not use this terminology to talk about their lives, and it therefore seemed problematic to impose such frames of reference upon their discussions. Nonetheless,

they did highlight issues of oppression, disempowerment and power relations in their accounts of experiences as mental health service users, using their own terms of reference. These comments can be considered in relation to the theoretical, conceptual and empirical literature reviewed to assess its robustness when applied to this group of mental health service users.

The use of the medical model of 'mental illness' as an explanatory framework

In exploring mental health service users' experiences of oppression and power relations for this doctoral work, it became clear that at the root of many of these experiences lay the biomedical discursive formation of distress as 'mental illness'. Although this medical model has been shown to be untenable on a number of counts (see p.35), it continues to dominate mental health treatment in Britain and to have a powerful cultural currency.

Foucault (1980:131) argues that scientific knowledge is key in producing 'regimes' or discourses of 'truth', which support power relations by constructing objects of knowledge such as 'the mentally ill' (Foucault, 1998). Psychiatry's success in establishing a 'regime of truth' whereby 'mental illness' is defined in biomedical terms and viewed as analogous to physical illness has led to many people, including some of those to whom the model is applied, accepting this particular discourse or interpretation of distress as 'truth'.

Foucault's argument is clearly supported by evidence from our project as co-researchers' acceptance of this biomedical conceptualisation of 'mental illness' was relatively strong, despite their negative experiences of psychiatry and the lack of evidence that this way of conceptualising their experiences had been beneficial for them in any significant way. All of the co-researchers identified themselves as 'ill', to the extent that Rose, for example, often used the analogy of physical illness to talk about her mental distress.

The group did not challenge this medical definition of their distress (in the way that the user/survivor movement is doing, as discussed on p.130), although they did question the consequences of the application of the medical model, such as the predominant use of physical treatments and hospitalisation. This finding also gives

support to Lukes' (1974) suggestion that power can be exercised by the subconscious manipulation of people's views, thereby encouraging acceptance of professional intervention. This appeared to be the case for co-researchers, in that they were still looking to professionals to provide *better* support rather than looking beyond statutory services, for example to other service users via self-help or advocacy groups.

The 'self-fulfilling' nature of the medical labels applied, as suggested by the labelling theory of 'mental illness' (Rosenhan, 1996; Scheff, 1996), could also be seen to have some relevance in our research. Most of the co-researchers involved tended to have had 'careers' as 'mental patients', with ongoing contact with inpatient and outpatient mental health services over many years, and much of their social interaction was with other mental health service users, for example at the drop-in centre. Their anxieties about using 'mainstream' services rather than specialist mental health services (highlighted on p.286) appeared to emanate partly from a sense of being 'other', and such differentiation has been identified as a key mechanism via which oppression is reproduced and maintained (see p.45-46).

The nature of oppression

Oppression has been defined in this dissertation as "the creation and use of mechanisms which sustain unfair dominance" (Keating, 1997:30), involving complex interactions between agency and structure. Keating's integrated model of oppression (described on p.43-46) has been proposed as a potentially valuable approach to understanding the nature of oppression[162]. Throughout this dissertation, attention has therefore been drawn to ways in which this model might be applied to empirical evidence on the nature of oppression experienced by mental health service users to assess its robustness.

Although no published literature could be identified which applied Keating's model to people with experience of mental distress, findings from this research project suggest that Keating's model can help to illuminate the nature of mental health

[162] It is recognised that attempting to develop a 'neat' model in relation to a phenomenon as complex and potentially irrational as oppression may be seen by some as problematic. Nonetheless, it is argued in this dissertation that such models, even if seen as 'ideal types', can nonetheless help to make sense of people's experiences and highlight different levels at which strategies to counter oppression might be required.

service users' experiences. For example, the psychological dimension of oppression was evident in the disrespectful, dehumanising and sometimes cruel treatment by both mental health and general health professionals described by co-researchers (for example on p.221-222). The socio-cultural dimension of oppression was also apparent in co-researchers' accounts of local opposition to a proposed mental health facility, and in their belief of the need to 'keep themselves to themselves' to avoid censure by neighbours (see p.230). With regard to the socio-political dimension of oppression, evidence from co-researchers suggested that they had encountered such oppression from a range of society's institutions, including medicine and housing providers. Within the institutional structures of psychiatry, co-researchers had been subjected to compulsory hospital admission and physical treatment, oppressive monitoring and surveillance, insensitive treatment by staff, and dehumanising institutional routines and practices (as described on p.220-225).

The common themes identified by Thompson (1993) and Keating (1997) across different forms of oppression (see p.40) were all at least implicit in co-researchers' accounts of a range of experiences of oppression and power relations (summarised on p.219). The interconnectedness of personal, socio-cultural and socio-political dimensions of oppression was clear in their comments, for example with regard to the exercise of professional power, as was the 'internalised oppression' (Freire, 1972) that tended to result from such experiences. Particularly during the initial phases of the project, co-researchers' comments highlighted negative self-perceptions, lack of confidence, limited outlooks on life, and feelings that life had been "ruined" due to their diagnosis of 'mental illness' (see p.237-238). The latter finding highlighted the need to acknowledge the significant impact of people's ongoing experiences of mental distress on their lives, as well as recognising the role that oppression and disempowerment plays in perpetuating that distress.

The nature of power

A conceptualisation of power which acknowledges the structural aspects of power and oppression (Thompson, 1998), yet also accounts for dynamic and fluid power relations between individuals and groups at different points in time, often linked to the production and reproduction of discourses, has been advocated in this dissertation (see p.60). Such a view accords with Layder's (1997:15) comprehensive

theory of power, and empirical evidence from our PR project suggests that such a multi-level, comprehensive conceptualisation of power can help to make sense of the experiences of people in mental distress.

Foucault's work, while exposing only some aspects of power's many forms (Layder, 1997), had considerable resonance with co-researchers' experiences. Foucault's (1980) emphasis on the close relationship between knowledge and power, and the corresponding creation of discursive formations that shape the way in which particular groups are understood and acted upon (see p.56), was relevant in that co-researchers largely accepted the medical discursive formation of 'mental illness', although some were less ready to accept the corresponding forms of professional intervention and 'treatment' than others.

Foucault's (1977:176) conceptualisation of disciplinary power could also be applied in different ways to co-researchers' experiences. The 'medical gaze' about which Foucault (1980, 1989) writes (see p.57) is an example of an instrument of disciplinary power, and was experienced by co-researchers as very oppressive[163] (as described on p.220). Foucault (1977:299) argues that such disciplinary power has spread beyond institutions to create a 'carceral society', characterised by continuous surveillance, which is internalised by individuals such that they undertake self-monitoring (see p.58). Such concerns were clear amongst co-researchers, for example in Sheila's awareness (highlighted on p.257) that she was being monitored by service providers to see how well she 'responded' to interventions (namely how well she conformed to social norms), and in her anxieties (provoked by correspondence with a social services manager) that drop-in centre users were being constantly assessed. Co-researchers' acknowledgement that they tended to isolate themselves from their neighbours so that they did not 'know their business' (see p.230) also suggested fear of such surveillance and potential sanctions.

However, the complexities of this operation of disciplinary power in society were evident in co-researchers' comments that they felt such surveillance did not operate extensively enough (see p.256-257), and that more monitoring and support in the

---

[163] This was particularly the case in situations of isolated observation and surveillance, as recalled by Rose and Sheila.

form of someone 'caring about what happens to them' would be welcomed. Foucault's idea of disciplinary power and corresponding surveillance can also be interpreted more positively in relation to the mental health user/survivor movement's self-management approach (described on p.94). In our project, Amy was attempting such self-management by not taking prescribed medication and instead seeking alternative forms of support and coping strategies.

Foucault's work on power has therefore been shown to be extremely valuable in highlighting discursive and disciplinary forms of power operating in the lives of co-researchers. Empirical evidence from our research highlights the complexity of the operation of Foucault's disciplinary power, with contradictions and tensions between people's fear of surveillance, their desire for some form of monitoring rather than being 'left to cope on their own', and the potentially productive nature of such power in relation to self-management strategies.

Foucault also emphasises the diffuse, fluid nature of power relations which permeate all social relationships (Foucault, 1998), an important consideration in analysing the myriad power dynamics in operation during our PR project (discussed on p.343-347).

However, limitations to Foucault's conceptualisation of power for understanding the way in which power may be experienced by mental health service users do exist, for example in relation to the role of agency, structural elements of power, and his view of power as primarily productive (explored in more depth on p.58-60). It is therefore important to combine Foucauldian analysis with a structural conceptualisation of power in order to acknowledge structural oppression experienced by people with experience of mental distress in society and structural constraints on their capacity to exercise power and control in their lives. It is vital to emphasise the way in which power is embedded in structures such as the State and other institutions (Porter, 1996) in any consideration of people in mental distress and their experiences of powerlessness in the face of institutions such as psychiatry.

The nature of professional power

With regard to power as an element of human agency, this was most evident in co-researchers' accounts of professionals exercising direct 'power over' them (see p.220-222, for example). These exercises of professional power were clearly legitimated by the professionals' structural position as agents of the state with a social control function. In addition to such direct exercise of 'power over' people, co-researchers also recalled occasions when professionals were exercising power by deciding upon resource allocation, and determining their needs for them (for example, p.227). In these respects, therefore, Wilding's (1982) typologies of professional power have been shown to be useful in exploring different forms of professional power and legitimising bases for this power[164].

Foucauldian theory suggests that fluid power relations operate between individuals and that resistance to professionals' exercise of power is possible, and this could be detected to some extent, for example in Amy's resistance of professional power by not taking her medication and in Sheila's challenges to health and social care professionals wanting to impose 'independence' on mental health service users.

<u>The extent to which PR can function as a strategy for empowerment for mental health service users</u>

Potential of PR as a strategy for empowerment

My review of methodological literature identified PR, as a social research methodology underpinned by the emancipatory paradigm, as potentially empowering for people with experience of mental distress (see p.179). PR aims in theory at least for empowerment at the individual, group and community levels, although the extent to which the latter is achievable and can result in social change has been questioned. Nonetheless, PR theory does resonate with the democratic models of involvement and participation outlined in Chapter Three, and at least aims to maximise involvement and participation of oppressed groups.

---

[164] It is acknowledged, however, that some of Wilding's (1982) assertions may be less relevant now with challenges to professional dominance from state-led modernising reforms (Means et al, 2003), the new public managerialism (Flynn, 1999), and service users themselves (Hugman, 1991).

Operationalising empowerment

Review of the literature on empowerment (presented in Chapter Three) led me to conclude that the liberational model of empowerment was more congruent with PR's aims than was the consumerist model (see p.104), as it also aimed to overcome oppression and discrimination to secure people's citizenship rights within society[165].

As argued in Chapter Three (see p.85), a view of empowerment as some form of outcome of an intervention risks oversimplifying this complex concept and ignoring the richness of process aspects of empowerment. Most authors writing on this subject have tended to define empowerment as a dynamic and fluid process operating at different levels and varying according to context and time span. From my review of the literature available at the time of designing this research project[166], I concluded that individual empowerment could most usefully be viewed as an ongoing process of personal growth and development (operational elements of which are identified on p.201). With regard to group empowerment, available literature suggested that this might entail processes of collective consciousness-raising via sharing experiences, participating in joint social or political action, and working to achieve some redistribution of resources or decision-making in favour of the group (p.201).

The strategies for empowerment reviewed in Chapter Four were also helpful in considering PR's potential, particularly as several of these could be seen to be operating within our PR project (e.g. group self-advocacy, mutual support and validation of experiences, consciousness-raising, collective organisation and action, and lobbying). As there are different levels of empowerment, so there are likely to be different levels of strategies for empowerment within PR.

Models of involvement and participation have also been reviewed in this dissertation[167], and it is concluded that the forms of involvement and participation

---

[165] The liberational model suggests that empowerment operates via processes of personal development which enable people to assert their needs and participate as citizens, and via encouraging change in social systems in order to develop inclusive services and structures (Barnes, 1997b).

[166] Literature reviewed was that published up to 1997: for example, Barnes, 1997b; Dalrymple and Burke, 1995; Gaster, 1996; Rappaport, 1987; Staples, 1990.

[167] For example, Croft and Beresford's (1993) democratic model of involvement, and Arnstein's (1969) ladder of citizen participation.

most likely to contribute to processes of empowerment as defined according to the liberational model are those in which service users have power and which facilitate their development as citizens with control over their lives as a whole rather than merely as service users functioning within professionally defined systems. The nature of involvement and participation facilitated by PR is therefore also an issue for consideration.

Research design to evaluate empowering processes occurring in PR

The research design for this doctoral work aimed to address the way in which the nature and extent of empowerment processes occurring during a PR project might be evaluated to meet my research aim of assessing the extent to which PR might function as a strategy for empowerment for mental health service users.

I made the decision to take a process-focused, qualitative approach to this evaluation, for several reasons (outlined in more depth in Chapter Six). These included: the intellectual and ideological contradiction between committing to undertake a PR project and then using an experimental positivist approach such as 'pre-' and 'post-intervention' standardised outcome measurement with 'intervention' and 'control' groups; the superficial approach to exploring complex processes involved in empowerment which such closed-category measurement would entail; and the inappropriateness of outcome measurement in a time-limited project due to the length of time often required for outcomes of empowering processes to occur (see p.202-203).

I therefore chose to adopt a process evaluation approach to considering the nature and extent of empowerment which may be occurring during PR (as advocated by Adams, 2003), using exploratory, open qualitative research methods to allow 'thick description' of the subtle and complex empowerment processes likely to be operating in such a project (see p.196-197). This decision has subsequently been reinforced by other authors who have advocated a qualitative process approach to evaluating empowerment (see p.203).

My decision to use such qualitative, naturalistic methods was also justified by co-researchers' reactions to methods of collecting information. During the project, co-

researchers made it clear that they disliked filling in forms and did not like the use of jargon, both of which were likely to have been involved had I asked them to complete standardised questionnaires. It also became apparent that they did not all feel comfortable in an individual interview situation. The use of observation to obtain evaluation data in an informal, naturalistic way therefore avoided alienating co-researchers from the research process.

I used the operational definitions of individual and group empowerment highlighted above in an informative rather than prescriptive way (see p.204-205), to sensitise myself to potential empowerment processes occurring during our PR project, and to guide my detailed observation notes, interviewing and subsequent data analysis. Furthermore, rather than using definitions of empowerment (and of power and oppression) from the literature to develop a pre-coded categorical framework for analysis (as would be done in a hypothetico-deductive research approach), data analysis was inductive (as discussed on p.207), with categories and themes allowed to emerge from the data gathered (Papineau and Kiely, 1996) and then compared with those from the literature to assess the extent to which they corresponded with or differed from previous writing on empowerment processes. In this way, I hoped to avoid 'narrowing' down description of co-researchers' experiences.

PR as a strategy for empowerment: fieldwork findings

Data sources drawn upon to assess the extent to which PR might facilitate empowerment processes included observational data gathered throughout the PR project, and evaluation interviews with co-researchers and the project worker. These multiple data sources function to triangulate the findings presented, in relation to both individual and group empowerment processes.

Individual empowerment processes

The extent of individual empowerment processes operating amongst co-researchers during each phase of the PR project can be detected from observational data. In the earlier phases of the project (Two and Three), most of the co-researchers (with the exception of Amy) appeared to have a relatively limited sense of personal power and control in relation to managing their symptoms of distress and living their everyday lives, and relatively negative self-definitions. With regard to information-seeking as

an empowering process, it was nonetheless clear that co-researchers were obtaining valuable information both from one another and from the project worker during group discussions. Another element of individual empowerment operating for some co-researchers in these earlier phases appeared to be validation of their own experiences via sharing them with others in similar situations.

The fourth phase of the PR project showed increasing confidence amongst co-researchers, which seemed to grow with each interview undertaken as they became more comfortable in asking professionals questions and in talking to them about their experiences. Co-researchers also obtained valuable information from the interviewees, which was often important for their personal situations. The research in which the group engaged during the fourth phase of the project could therefore be seen as contributing to their individual empowerment by developing their knowledge (and to an extent their research skills), asserting their personal needs and enhancing their sense of personal power and confidence. In the fifth phase of the PR project, the successful action in which co-researchers engaged appeared to contribute to processes of individual empowerment via the knowledge, skills and confidence gained through activism.

In evaluation interviews, benefits identified by individual co-researchers from their participation in the project (explored on p.307-309) can be summarised as: increases in confidence; finding it easier to speak out; obtaining a better knowledge of systems; having the opportunity to share their experiences with people; being able to ask professionals questions and receive answers; and taking action to improve their situation, all of which have been identified in the literature as elements of individual empowerment processes. Co-researchers also felt that they had achieved change for other people, not just for themselves. Similar to the co-researchers, the project worker identified the operation of a range of empowerment processes for individual co-researchers, including improving confidence and self-esteem, obtaining information, using their voices to express their needs, and enhancing their skills.

Group empowerment processes

The sharing of experiences and associated collective consciousness-raising occurring during Phases Two and Three of the PR project can be identified as a group

empowerment process, as can the mutual support which was emerging between co-researchers. The investigation undertaken by the group during the project's fourth phase also contributed to collective empowerment by providing the basis for joint social action (particularly on transport). Collective consciousness-raising also took place in the fourth phase, for example co-researchers learning more about how their experiences linked to policies of community care provision and service closure.

An important element of group empowerment processes has been identified as engaging in joint action to achieve some redistribution of resources or decision-making in favour of the group. Action of this nature took place during the project's fifth phase, contributing to a stronger sense of entitlement and power to influence conditions amongst co-researchers.

Co-researchers' interview comments on their experiences in the PR group also emphasised the satisfaction they felt from participating in joint action to achieve change, and the value they drew from sharing experiences (see p.309). In their evaluation interviews, co-researchers expressed a strong sense of the group working together to achieve change, using their collective voice and influence. Sue also identified the sharing of experiences, and the joint action undertaken by co-researchers to obtain improvements in resource allocation and service configuration, as important achievements of the group[168].

It should be noted, however, that individual and group empowerment are not necessarily linked. I concluded that co-researchers engaged in group empowerment processes, but nonetheless not every co-researcher engaged in processes of individual empowerment. Maria, for example, clearly enjoyed the interview with the GP and was pleased to share her experiences with her, but it was not apparent that the experience had been empowering for her in the same way as it had been for other co-researchers. Benefits of participation for David were also limited by the fact that he joined halfway through the project, therefore missing the important early phases of sharing and validating experiences. Those who gained most benefit from

---

[168] Both of these processes have been identified in the literature as group empowerment processes (Gaster, 1996; Rissel, 1994).

participating in the group appeared to be co-researchers who had been involved and engaged from the start of the process, reinforcing the importance of maintaining continuity throughout such a project.

It is important to note that people with experience of mental distress are increasingly emphasising recovery as a new paradigm for conceptualising their experiences. The literature on recovery overlaps with much of that on empowerment in its common emphasis on regaining control over one's life, re-establishing a positive sense of self and purpose, making choices and exercising self-determination, and supporting others. It can be seen that empowerment, in the liberational sense, is considered by people with experience of mental distress to be critical to their journeys of recovery. While recovery was not a concept raised by co-researchers in our project, it may nonetheless be argued that on the basis of the evidence from our work, involvement in PR could also contribute to people's journeys of recovery.

Limitations of PR as a strategy for empowerment

Despite the encouraging findings in relation to processes of individual and group empowerment processes occurring during our PR project, it is important to highlight limitations of PR methodology which may have constrained the extent of this empowerment.

The first of these relates to PR's emphasis on 'problematising' people's experiences (see p.185). In contrast to the positive, strengths-focused approach of empowering practice methodologies such as those used in social work (see p.175), the PR framework used for this doctoral work (Maguire, 1987) began with an exploration of people's problems and negative experiences. While this sharing of problems could in itself be empowering (as noted by co-researchers who found this beneficial), and is seen in PR as a prerequisite to people then identifying solutions, it nonetheless introduces a relatively negative tone in the early stages of the project. It is suggested that the empowering nature of PR could be enhanced by making it a more explicitly strengths-focused methodology from the outset, and locating people's experiences and problems within the context of the strength that they have demonstrated in surviving these experiences.

PR has also been criticised for leaving ultimate control of research with the 'external' researcher rather than with the co-researchers involved, highlighting the importance of the researcher attempting to alter these social relations of research production as much as possible (Finkelstein, 1999; Oliver, 1997). However, this criticism may relate to the rather simplistic and 'zero-sum' view of power implied in the 'researcher/ researched' relationship as conceptualised in PR. If, instead, a more Foucauldian approach is taken, emphasising fluid power relations between people, it can be seen that PR nonetheless enables co-researchers to exercise power in many ways within the research process.

While PR theory accords with the liberational model of empowerment's aims of changing the position of oppressed groups in society, evidence of empowerment at a structural level as a result of our project was not apparent. Our experience suggests that a project would need to be established on a much larger scale and a more long-term basis to be able to have some influence on structural conditions, yet such projects then run the risk of becoming less participatory. It might be concluded that such social change is more likely to be achieved via other strategies of empowerment, such as lobbying and direct action, with PR contributing to these strategies via knowledge production and consciousness-raising. Indeed, Barnes and Bowl's (2001) suggestion that action from within service systems or user groups is unlikely to be able to address structural dimensions of inequality and achieve structural change is borne out by our experience.

Our project could not therefore claim to have had an influence in line with the liberational model's structural level of empowerment, although the individual level of empowerment within the liberational model (see p.81) was more apparent in terms of co-researchers' personal growth and development leading to the exercise of more influence in their lives. This does raise the issue of exactly how processes of individual empowerment can lead on to structural empowerment. It is not clear within the liberational model of empowerment, nor within PR theory, how such a move might occur, and further work would be valuable to illuminate what strategies might be adopted in order to achieve this structural change. Nonetheless, PR projects such as ours might be seen as a first step in the process of empowerment in the liberational sense, by facilitating the development of people's power both

individually and collectively, which they might then use to work for broader social change.

The extent to which PR methodological principles can be adhered to in research with mental health service users, and issues for PR methodological development

The PR literature suggests certain key methodological principles to which projects should attempt to adhere (highlighted on p.167-169), all underpinned by a clear value base which views oppressed people as self-determining agents capable of finding solutions to their own problems and taking action to counter their oppression. This section discusses the extent to which our PR project adhered to these principles[169], as well as drawing conclusions about informed consent, and the 'validity' and 'reliability' of the project findings.

Processes of investigation, education and action

Our PR project was structured in a way that facilitated the operation of processes of investigation, education and action. The consciousness-raising aims of facilitating the sharing of experiences and identification of common problems via dialogue were occurring from the start of the project. My attempts to initiate a formal educational phase of the project were largely unsuccessful, however, as co-researchers appeared more comfortable talking about the nature of their problems and experiences than about the reasons behind these. An important finding for me was to use co-researchers' terms of reference and ways of looking at experiences rather than thinking that it might be possible to impose upon them a theoretical framework of reference for these experiences. Nonetheless, educative processes still took place for co-researchers, both in the form of learning from one another's experiences and from the interviews undertaken.

Investigation took place via the project's very successful research phase. Co-researchers took a range of actions, including lobbying the social services department, speaking at a PAG meeting, undertaking a survey to reinforce their

---

[169] As very few issues about the PR methodology and process were raised by co-researchers and the project worker in their interviews, these conclusions are primarily based upon observational data and my reflexive journal entries.

action, asking the host organisation to lobby on their behalf, and analysing and interpreting correspondence.

Overall, experiences in our project were similar to those of Maguire (1987). Maguire's PR framework therefore seemed to be an appropriate way of carrying out PR, as its phases led our group clearly through processes of investigation, education and action. However, some amendments to Maguire's framework occurred as the project progressed.

Phases Two and Three of Maguire's framework were effectively combined in our project, as the limited analysis the group wished to undertake in relation to the wider structural context of their experiences occurred during the 'problem-posing' phase. Adequate time to prepare for carrying out research was very important in Phase Four, to enable people to feel confident in undertaking research. Maguire does not focus upon this preparation, which should be explicitly included in Phase Four. Another amendment to Maguire's framework suggested by our project would be an extension of Phase Five, from 'definition of action' to include taking action. In reality, definition of action to be taken was occurring during Phase Four, as we collected data from our research activities.

I also incorporated into the research design a sixth phase, to end the project. It was helpful to introduce this idea of ending some months before it would be happening, so that co-researchers had some sense of the time-limited nature of my involvement. From our experience, there is also a need to place more emphasis on 'handing over' work started in a PR project, to continue this work and integrate it with other community activities. Therefore, a sixth phase of PR, to modify both Maguire's (1987) and Northway's (1998) work, might be ending the research project and building links with other work to sustain long-term participation (thereby increasing possibilities for social change).

Our experience therefore suggests that while Maguire's (1987) original framework was a useful starting point from which to design a PR project, it can usefully be adapted as follows:

- Phase One: Organisation of the project and knowledge of the working area (as per Maguire);
- Phase Two: Problem-posing, and linking individual interpretations of problems to the broader social and structural context (combining Phases Two and Three of Maguire);
- Phase Three: Preparing to research, researching social reality and analysing collected information (adding a preparation phase to Maguire's Phase Four);
- Phase Four: Definition of action projects, and undertaking action (adding undertaking action to Maguire's Phase Five);
- Phase Five: Ending the research (as per Northway, 1998) and linking work with ongoing community action in order to effect social change (a new phase not covered by Maguire).

Such adaptations are made on the basis of the experiences of our project. Nonetheless, it is important to emphasise that these suggestions are proposed as an alternative rather than superior approach to PR, as research practice is likely to vary depending on the context and groups of people involved.

With regard to moving through these phases of PR, Evans and Fisher (1999) reported from their research with a user-controlled group that:

> Few members had undertaken research, but most had received services, and it was difficult at times for members to move on from recounting their experience to using it to inform decisions about research detail, such as what the areas of questioning should cover. (p.110)

This was similar to our experience, as co-researchers often returned to discuss their experiences during later phases of the project. However, this demonstrates the value of such exploration and sharing of their experiences, and should not be discounted as a potentially empowering strategy in itself. In our experience, PR's phases also tended to be interwoven and did not have a clear ending at any stage[170]. It is therefore concluded that the conceptualisation of PR in 'phases' can be helpful to structure a project, but should not be used to 'close down' possibilities for further

[170] For example, Phase Five commenced while Phase Four was still ongoing, as co-researchers started to take action on the transport issue. Indeed, it was difficult to separate out the research and action elements of the project. For example, the interviews with professionals were part of the research, but also involved action as co-researchers told professionals their views. In addition, we used the research method of a questionnaire survey during Phase Five to inform the action we were taking on transport.

work in any of the phases as the project progresses. Co-researchers' wishes should determine which PR activities are taking place at any one time.

The action phase of PR was very important in our project, particularly with regard to supporting action through to positive outcomes, to avoid further disempowerment of co-researchers. Therefore, it is important to ensure that PR projects result in action, defined by the co-researchers, wherever possible. If such action appears unlikely during the project's life, it might nonetheless be achieved by integrating the project's work with other community work and action.

Indeed, in order to increase possibilities for emancipatory social action and change resulting from PR, it has been suggested that PR should ideally form part of an ongoing and long-term process of participatory activity, social action and change in communities (de Koning and Martin, 1996a). Our experience would appear to reinforce this suggestion, in that some of the work did continue via the host organisation's activities, and co-researchers were looking for opportunities to continue to make their voices heard and effect change (as witnessed by their request to reconvene our group). Nonetheless, the participatory work and action developing from our project could have been further enhanced had it been linked into a broader community programme of action.

Informed consent in PR

Informed consent is traditionally obtained from research participants at the start of a research project, after explanation of confidentiality, anonymity, the research conditions and people's right to withdraw. Such explanation took place at the start of this project, and I asked participants to sign consent forms to take part (Appendix 1). However, PR emphasises taking the lead on research design from the community involved, and I had therefore tried not to guide people too much in the project's initial stages with regard to what might be involved. The extent to which people were clear about what they were consenting to take part in was therefore questionable.

As suggested by Knox et al (2000) and Northway (2000b), our experience confirmed that informed consent might be better viewed within PR as a process that emerges

during the project. While initial consent to participate may be obtained, it is then important to ensure that regular 'checking back' occurs, asking if co-researchers are happy with how the research is progressing, how information is being produced, and the research conditions[171].

Redistribution of power and control

This project was established at my initiation, and I planned to attempt to work to a predefined research framework as part of my doctoral studies. With this in mind, it would not have been possible for co-researchers to be fully in control of this research project as I predetermined its structure and guided co-researchers through this[172].

Participatory researchers have suggested that co-researchers may not wish to control the entire research process, possibly due to other priorities in their lives (Tetley and Hanson, 2000). For example, Martin (1996) found in her feminist PR project that the women involved asked her to choose the research methods, as they had limited time to take on more work and felt that she had the skills to do this. In such cases, it is important that co-researchers decide at which points in the research process they wish to take control and at which they would like to use the external researcher's skills as resources.

The possibility of group members becoming dependent on the participatory researcher, rather than the researcher working to hand over the research facilitation, has also been highlighted (Fine et al, 2001). Transfer of this organisational role could be viewed as important if PR projects are to contribute to a sustainable process of action and change beyond the researcher's time-limited involvement (McDonald, 2001).

However, an important finding in our project was that co-researchers did not want to take control in terms of organisation of the group or its activities. I encouraged co-researchers to take on organisational roles at points[173], but on each occasion the

---

[171] I undertook such checking back during our project, for example via review sessions, and felt satisfied that people did understand the research conditions and were happy to be taking part on that basis.
[172] Co-researchers could have challenged this structure, however, but did not do so.
[173] For example talking at the centre users' meeting about our research, carrying out the transport survey, and chairing the group interviews.

group stated that they wanted me to take on these roles. This may have been partly due to co-researchers' fears about taking on such new roles, but also to my failure to establish the project in a way that would have made it clear that my organisational role was only intended as an initial one until the group became more established and confident[174]. I could have attempted to force this issue by insisting that co-researchers took on such roles. However, I believe that such attempts could have been damaging to relationships with the group, and would also have represented an imposition of my agenda, as someone trying to work to PR principles of encouraging co-researcher control.

It may be unrealistic to expect co-researchers to have the confidence to take on such organisational responsibility in a project's early stages and it may therefore be appropriate for the 'external' researcher to provide such enabling organisation. While some disability writers argue that PR cannot be viewed as emancipatory as it does not accord full control of all social and material relations of research production to service users (Oliver, 1997), it is evident from our experience that PR can nonetheless be valuable as the first stage of a process of facilitating users' participation and involvement in research, particularly for people unaccustomed to being involved in such work (as was the case for our group). It might be more helpful to think of PR as working *towards* a full reversal of the social and material relations of research production, *in line with co-researchers' wishes*, than to insist on such a reversal from the outset of any project. Research infrastructure and skills were available to co-researchers as resources from the 'external' researcher, which appeared important for our group as it was formed specifically for this project and its members had no previous experience of undertaking research[175]. This assertion is reinforced by Lindow's (2001) recognition of the value of such external support for survivor researchers.

Nonetheless, it is conceded that PR does involve external researchers exercising some control over the research process, often having responsibility for funding, and

---

[174] I acknowledge that I may have failed to emphasise this due to the nature of this project as contributing to my doctoral studies and therefore my anxieties about having a 'successful' project.

[175] It has been argued in Chapter Five of this dissertation that the kind of emancipatory research advocated by the disability movement appears to be feasible only for people already politicised and involved in groups with some form of infrastructure to support their activities.

often controlling dissemination of results (Kemshall and Littlechild, 2000). In these senses, PR is limited in the extent of power and control that it concedes to co-researchers throughout the research process. Suggestions that PR is more concerned with promoting participation, and ER as defined by disability writers (see p.176) is focused upon control, i.e. is further along the continuum of participation discussed earlier (Northway, 2000a; Walmsley, 2001), therefore appear to have been validated by our experience.

With regard to the extent to which I relinquished power, I attempted to share power with co-researchers throughout the research process in terms of the content and nature of discussions, and the decisions that were made about the group and its work. The group tended to look to me for guidance with regard to decisions to be made in initial phases of the project. However, by the project's fourth phase, co-researchers were increasingly willing to take decisions about the project's direction, demonstrating that they were beginning to take control of the research process.

Nonetheless, I retained a certain amount of power due to my structural position as an academic researcher with access to institutional resources, encouraging a group to work to a predefined research design. My knowledge of and access to professionals and service systems also placed me in a more powerful position than my co-researchers, although their knowledge of these systems did increase as the project progressed (and my power in this situation could be viewed as productive and enabling).

With regard to the group's ending, I was aware that I was exercising a form of power quite strongly (as was the host organisation) by imposing an ending on the group which did not necessarily coincide with their needs and wishes, at a time when they were still taking action[176]. This reflects Wilding's (1982) identification of professionals' imposition of their needs and wishes on service users, for their convenience rather than for that of service users. Unfortunately, I could not avoid exercising power in this way due to the need to progress with the academic work

[176] This imposed ending was necessary in order for me to commence analysing the significant volume of data collected for this dissertation.

required for my doctoral studies, but I was acutely conscious that in doing so I was potentially contradicting co-researchers' wishes (discussed on p.295).

In addition, I imposed evaluation interviews on co-researchers, for my benefit rather than theirs. Co-researchers would have been unlikely to choose to take part in such interviews were this not also an academic research project. Tensions between my role as a research student attempting to meet academic requirements for doctoral work, and my role as a participatory researcher wanting to enable co-researchers to fully determine the nature and extent of the project and its activities, were therefore apparent throughout our work together. This highlights the need for honesty with co-researchers from the outset about the 'external' researcher's agenda and requirements. Nonetheless, it does not mean that it is not possible for co-researchers to also achieve benefits from the research.

While PR emphasises the need to reverse power relations so that the external researcher 'hands over' power to co-researchers, this relatively simplistic binary conceptualisation of power masks other power relations which might be operating in such a situation. For example, power dynamics operated between co-researchers, with certain co-researchers dominating discussions and sometimes discouraging other co-researchers from participating, which can be seen as having constrained the access of all co-researchers to equal power within this process. Similarly, the project worker's presence at group sessions may have influenced and constrained co-researchers' behaviour and confidence in taking decisions[177].

The power dynamics occurring during interviews with health and social care professionals were interesting, with a less marked power imbalance between co-researchers and interviewees than might be the case in a 'professional/service user' interaction, yet still some element of deference to the professional's structural authority and expertise, particularly in the case of the GP. Therefore, while co-researchers were challenging the traditional power relationship between service user

[177] However, co-researchers did appear comfortable to criticise the host organisation in Sue's presence and hence the extent to which her presence functioned to constrain co-researchers' actions is difficult to ascertain.

and professional by questioning them in this way, elements of this power dynamic were still apparent even in this novel context.

The way in which the host organisation manager chose to exercise power in relation to our PR group was also contradictory, constraining the group's activities in some important ways while encouraging its members to exercise power in other situations. It may be that the manager was supportive of 'user involvement' work, but preferred this to be within her remit and control, rather than occurring 'independently' via our group. This highlights the danger that participatory work such as ours may become co-opted by organisations for their own agendas, which may not be underpinned with a similar commitment to encouraging user control of the agenda and activities.

The 'gate-keeping' role of the host organisation was difficult to avoid in our project, and limited my communication with co-researchers. This exercise of power with regard to ownership of individuals' contact details, while clearly done to protect people's confidentiality, demonstrated the way in which co-researchers were seen by the host organisation as 'belonging' to them. Such an issue could be avoided by carrying out PR with independent user groups. Nonetheless, I feel that PR also has value for less politicised people, as was the case with our group, and that in such cases it may be necessary to 'gain access' to people via such a gatekeeper. However, the host organisation's support did mean that the group's work was sustained and developed to some extent beyond the life of our project. It is therefore concluded that involvement of an organisation supporting PR work can be beneficial in terms of support to individuals and long-term sustainability of that work, but that such involvement should be carefully negotiated to maintain 'independence' for the PR group and its work. Researchers need to work to ensure that the PR group's agenda is foremost and is not subsumed within the agenda of other individuals or organisations with potentially competing interests.

Participation in all stages of the research process

Although I initiated the project for my studies and decided the aims of this doctoral work, co-researchers self-selected to take part in the project, which I deliberately described only vaguely at first (to avoid influencing the way in which co-researchers

chose to shape the research), and co-researchers then chose the topics they wished to research (based upon their discussions of experiences).

Co-researchers participated fully in carrying out research, deciding on research methods to use, who to invite to be interviewed and how the interviews would be conducted, preparing questions to ask interviewees, and carrying out the interviews. Co-researchers also decided to undertake a questionnaire survey to support their action on transport. It is important to note that the knowledge which co-researchers obtained from their research was of a particular quality, with co-researchers asking very specific, practical questions grounded in their own experiences (rather than in policy rhetoric), which pushed professionals to respond to them honestly regarding constraints on professional practice. Co-researchers' analysis of these findings was different to traditional 'academic' analysis in that they reflected upon the information they had obtained primarily in relation to action that they wanted to take.

Co-researchers participated fully in this action, driving the work forward and taking the initiative to draw in other service users and workers to support their action. Although the outcome of these actions was not apparent until after the group had formally ended, it did achieve positive results in relation to transport and benefits (as highlighted in Chapter Ten).

Co-researchers were not involved in disseminating or 'writing up' the research as they did not respond to my suggestions to do this (for example by writing for a newsletter)[178]. Co-researchers were more interested in taking action on the information they had obtained than they were in writing about this information. Nonetheless, in order to contribute to the development of theory and practice both in relation to PR and to carrying out research with oppressed groups, it is important that some dissemination of research findings occurs. If co-researchers do not express an interest in this, then it could be argued that the external researcher should bear some responsibility for undertaking such dissemination even if this is not a fully participative process[179].

---

[178] Nonetheless, one co-researcher did accompany me to a conference at which I was presenting a workshop on the project.

[179] It is also important that such dissemination occurs to a wide audience, namely service users, professionals, policy makers and academics, in order to maximise the practical impact of the work.

It should be noted that participation throughout the PR process was affected both by practical issues such as transport but also by co-researchers' changing mental health. It is important that this variation is recognised and respected by participatory researchers working in this way with mental health service users, and that projects remain flexible enough to accommodate people's changing circumstances. It is therefore suggested that to maximise participation in PR, a project should be flexible enough to accommodate varying attendance, should involve enough people to maintain a 'critical mass' of co-researchers to make group decisions, and should ensure that accessible information is produced and provided to all co-researchers throughout the research process[180].

Gender and ethnicity

In acknowledgement of the multiple oppression experienced by many people using mental health services (as discussed in Chapter Four), Maguire (1987) emphasises the importance of attending to gender issues throughout the PR process. I was conscious of this requirement, particularly as the project was based upon Maguire's work. Although clearly contextualised by structural inequalities in relation to gender (see p.29-30), stereotypes were less obvious in relation to gendered participation within the group and it seemed possible for women's voices to be heard in this context. People's contributions to group sessions and the group dynamics seemed to be influenced more by the personalities of the people involved and the nature of their relationships than by their gender.

Issues of ethnic and cultural difference within a group are also likely to influence its dynamics and the participation of group members. Maria was the only member of our group whose first language was not English. Her language difficulties made it more difficult for her to participate, although I attempted to read through any written material with her, and to involve her in discussions. However, other co-researchers sometimes became impatient with Maria, whose communication style was quite erratic. I attempted to manage such impatience by continuing to focus on Maria and her contribution. However, the issue arises of whether I should have directly

---

[180] The production of regular written information was found to be a valuable way of updating co-researchers on the project's progress.

confronted the co-researchers involved about their attitudes. I did not do so as I was anxious not to alienate them from the group. In addition, it was hard to ascertain whether the agitated nature of some of Maria's contributions was due to her language difficulties or to her varying levels of mental distress.

However, in not confronting other co-researchers about the reasons for their impatience, I may not have adequately supported Maria. Indeed, the project worker felt that Maria had withdrawn from the group because of the hostility she had experienced from some co-researchers. It would therefore seem important to address such issues both as they arise in a PR project, and at the start of the project via some explicit commentary on valuing diversity and incorporation of such issues within the negotiated ground rules, in order to maximise the participation of all co-researchers.

New role for 'external' researcher

Humphries et al (2000:13) suggest that emancipatory research should locate the 'self' within the process, focusing upon personal, social and institutional influences on the research process. Reflexivity is a key aspect of the researcher's role in PR, both with regard to the research context and to relationships with the research participants.

In terms of my 'right' to undertake such research, I felt that my personal experiences with people in mental distress (see p.163-164) gave me some basis for working with a group of mental health service users in this way. I recognised that I had not received a diagnosis of 'mental illness' and therefore could never fully understand the implications of such an experience, but hoped that working according to participatory and emancipatory principles would ensure that I as a researcher did not contribute further to marginalising people's experiences. In a review session at which I was not present, co-researchers stated that they appreciated my approach to the research, felt comfortable with me, and felt that I seemed to understand the issues they were raising (see Appendix 11, p.454). I hoped that these comments gave some justification for my continued involvement in this work.

Nonetheless, I was also conscious of the responsibilities which undertaking such research entailed, particularly due to my relatively privileged social position as a

middle-class woman working in an academic institution. I very much wanted to ensure that the research resulted in material benefits for the co-researchers, as I hoped to obtain such benefits in the form of being awarded a PhD, and aimed to use my privileged position within a university to access valuable resources for the group, for example using my existing contacts with the social services councillor and health authority manager to encourage their attendance at interviews. I was also concerned that co-researchers might be disappointed if their hopes were raised but not met by action taken, as co-researchers had taken some risk in engaging in such a process with me and challenging organisations in this way. I tried to avoid such disappointment by emphasising that any action taken might require time to yield results due to organisations' bureaucratic structures, and by 'handing on' the group's work to the host organisation to pursue.

Nonetheless, the project worker reported to me that some co-researchers felt frustrated that action had not led to positive 'results' during the group's time together, even though this action did then lead to the establishment of the pilot subsidised taxi scheme soon afterwards. This highlights the potential for PR to be a further source of disempowerment for marginalised groups if action taken is not successful. Correspondingly, there is an important need to make clear such possibilities with co-researchers from the outset of such a project, to support people through processes, and to attempt to maximise the possibility of successful action by linking into ongoing community work aimed at social change.

The role of researcher that I attempted to adopt, in line with the PR literature, was that of group facilitator and enabler, presenting my skills as resources to be used by co-researchers. My role was also process- rather than outcome-orientated, in that the processes of dialogue, participation and involvement operating were clearly important to co-researchers and I worked to facilitate these rather than focusing solely on what the group might achieve. It is therefore recommended that any researcher wishing to undertake PR should be experienced in facilitating groupwork, or should receive training in order to develop such skills.

My experience in this project of other skills required by participatory researchers mirrored those reported in the literature. Important skills to draw upon included

active listening skills, as listening to people who were not used to being heard was a vital element in developing their confidence in the project. An ability to engage with people was also important: PR involves building up close relationships with people over a relatively long period of time, and a researcher should consider whether they desire that sort of research relationship before embarking upon a PR project. Flexibility was a key attribute, as attempting to hand over control to other people meant that I had to be prepared to follow their agenda rather than my own. I concluded that academics should have training for involvement in PR, not merely in its theory but also in practical skills and issues such as groupwork, facilitation, active listening and valuing diversity.

Like other accounts in the literature, I found that PR placed great demands on my time. I was involved in weekly group sessions, followed by weekly transcription of the sessions, producing summaries of these transcriptions, and preparing for the following week's session. This work was tiring but I felt essential as people could see the knowledge that they had produced and could use it as the basis for further discussion and knowledge production. Any researcher deciding to undertake PR should be fully aware of the time involved, and should ensure that they are able to dedicate such time if participatory principles are to be adhered to.

Data analysis in PR

PR methodological literature does not tend to include exploration of how to undertake and present data analysis, particularly in relation to group data and longitudinal data analysis. This may be because the knowledge produced in PR is primarily intended as a basis for action rather than for academic analysis. Nonetheless, for academic researchers involved in PR, the analytic dimension is important, not least in order to identify ways in which PR methodology might be further refined to better meet its espoused aims.

I have therefore attempted to analyse and present data in some detail in Chapters Seven to Ten of this dissertation. I would suggest that this contributes to illuminating the 'real world' of PR, rather than presenting a fictionalised account. Presenting co-researchers' voices in the text also highlights their involvement as more than just research participants.

I developed a structured approach to data analysis using the 'Framework' approach (Ritchie and Spencer, 1994), methodically identifying themes and applying codes to all session transcripts and to my reflexive journal. This was a very time-consuming approach, but helped to ensure that I was able to draw out a range of themes from all of the data, including the operation of empowerment processes and power dynamics, and adherence to PR methodological principles. This allowed themed presentation of results which linked clearly to my research aims.

It is therefore concluded that it is possible and desirable for researchers writing about PR to be explicit in their accounts of how data analysis has been undertaken. A structured approach to data analysis, exploring themes within the full range of data sources, was found to be a helpful approach in this project, particularly in the light of the longitudinal and 'group' nature of much of the data.

'Validity' and 'reliability' of PR findings

As highlighted in Chapter Five, questions of 'validity' and 'reliability' cannot be applied to PR projects as they are to positivist research (see p.173-174). As PR aims to produce "situated knowledges" (Dockery, 2000:98), generated in specific circumstances by particular people, emphasis has been placed on considering "the project's assessment and representation of the experiences of the participants, and the project's 'catalytic validity' or capacity to mobilize action" (Finn, 1994:35).

It is argued from the evidence presented in this dissertation that our PR project succeeded in accurately representing the experiences which were considered important by the group of people involved in that context at that particular time, an assertion validated by the fact that co-researchers returned to repeat these experiences several times over the course of the project.

Our PR project also succeeded in obtaining information that mobilised action, as co-researchers took interview findings and used them to take action to secure improved transport. In this sense, our PR project met Finn's (1994) requirement that PR should produce knowledge that is relevant for facilitating empowerment for the group involved, considered to be more important than whether this knowledge was

reliable in the sense of being 'reproducible'. However, it is noted that many of the comments and experiences of co-researchers did echo those of other mental health service users reported in the British literature (see Chapter Four), which also serves to 'validate' the findings of our work.

Conclusion

This chapter has critically analysed theoretical, conceptual, empirical and methodological literature explored in earlier chapters of this dissertation in the context of fieldwork carried out during our PR project. This critical analysis has included consideration of the robustness of theories and frameworks outlined earlier, adaptation of frameworks undertaken for this doctoral work, and suggestions for future development of PR methodology and empowering research practice. This analysis has been undertaken in three areas relating to the research aims: the nature of oppression and power in the lives of mental health service users in Britain; the potential of PR as a strategy for empowerment for mental health service users; and the extent to which PR methodological principles could be adhered to in our project, and consequent issues for methodological development arising from our experience.

The final chapter of this dissertation identifies the original contributions to knowledge advancement made by this doctoral work in relation to these three key areas of study, and highlights some implications for research, policy and practice.

Chapter Twelve: Conclusions

Introduction

This concluding chapter draws out key findings to demonstrate ways in which this doctoral study has made original contributions to knowledge advancement, in relation to its research aims. It then considers some implications of these findings for developments in research, policy and practice.

It is important to acknowledge that this work was undertaken with a small group of mental health service users in one particular area of England, and conclusions presented are therefore based upon this specific experience. Nonetheless, the findings from our work mirrored experiences recounted in other British literature, and it is hoped that these conclusions are still of relevance and interest to a wide audience. This audience is likely to include mental health service users/survivors, researchers, professionals and policy makers.

Original contributions to the advancement of knowledge

'Originality' of contributions to knowledge advancement can be interpreted in different ways. Cryer (1996) and Murray (2002) suggest that original contributions can include: undertaking empirical work that has not been done before (in a particular country); synthesising work that has not been put together before; taking an existing technique and applying it to a new area; testing or adding to existing knowledge in an original way; developing or improving existing theory or methodology; and using research tools or techniques in new ways. The following section demonstrates ways in which this doctoral work has made original contributions to knowledge advancement in all of these ways, presented in line with the research aims.

The nature of oppression and power in the lives of mental health service users

This doctoral study explored the nature of oppression and power relations in the lives of mental health service users in Britain by undertaking empirical work in the form of a PR project with long-term mental health service users in a voluntary day service setting. These service users were not already members of an organised user/survivor group. My reviews of published and 'grey' literature did not identify any other examples of PR undertaken with mental health service users in this particular setting and set of circumstances in Britain. This doctoral project is therefore an original piece of empirical work, taking an existing methodology and applying it to a new area. Furthermore, British examples of such exploration of mental health service users' experiences of oppression and power relations via PR are rare, and this doctoral work makes another original contribution by adding to existing knowledge on this subject in a novel way.

An important part of this work was to undertake a critical analysis of theories of oppression and power in relation to empirical evidence of mental health service users' experiences in Britain (both from published literature and from our PR project). I could not identify such a systematic synthesis of theoretical, conceptual and empirical literature on this subject in any published literature, and therefore contend that this also represents an original contribution to knowledge advancement.

For example, Keating's (1997) integrated model of oppression does not appear to have been systematically applied to the experiences of mental health service users in previous published work. Indeed, much work that refers to the oppression of mental health service users does not clearly define what such oppression might entail. For these reasons, the finding that Keating's model is applicable both to co-researchers' experiences of oppression and to the experiences recounted in the broader British literature is a valuable contribution to work in this area.

Similarly, the conceptualisation of power as a multi-dimensional phenomenon, forming part of human agency, individuals' psychological make-up, discursive practices, and society's structural parameters (Layder, 1997:15) has been shown to resonate with both co-researchers' experiences and those recounted in other British studies. This finding contributes to developing a deeper understanding of the

complex power relations that mental health service users have to negotiate in their lives. Combined with acknowledgement of the power embedded in social structures, Foucault's work in particular makes an important contribution to understanding mental health service users' experiences of power, for example in relation to discourse, disciplinary power, and resistance to power exercise. There are few published examples of such theories of power being explicitly applied to empirical evidence of mental health service users' experiences, yet this doctoral work suggests that theory can help to illuminate the nature of power relations operating and as such can valuably be applied in research with mental health service users.

Finally, it is noted that many of the experiences of oppression and power related by co-researchers closely corresponded to those documented in other British research studies on this subject. Findings from this doctoral work therefore contribute to the existing body of empirical work, and enhance understanding of this empirical evidence by embedding it more explicitly within relevant theoretical and conceptual frameworks.

The extent to which PR can function as a strategy for empowerment for mental health service users

This dissertation makes an important original contribution to knowledge advancement by systematically applying empowerment theory to PR theory and practice via empirical work with mental health service users, thereby testing existing knowledge on empowerment in an innovative way. This work has provided a clearer framework within which to consider the potentially empowering nature of PR. Although it is acknowledged that empowerment is a contested concept, participatory researchers often fail to define what they consider empowerment to be when they make claims to PR's potential in this regard. Such claims to 'empowering practice' are also made by other researchers working in participative ways, often without any exploration of what empowerment might entail. By being explicit about the meanings and levels of empowerment, this dissertation has therefore contributed a more systematic exploration of empowerment processes operating within a PR project than has been presented within the British literature to date.

This systematic application of empowerment theory to the PR project undertaken has demonstrated that PR does have potential as a strategy for individual and group empowerment for mental health service users in Britain (see p.334-337). Its potential for empowerment at the structural level is likely to be maximised in combination with other strategies for empowerment, such as social action and campaigning, on a long-term and large-scale basis. Joining together with other oppressed groups such as groups of disabled people to work on areas of common interest may also make PR, undertaken alongside other strategies for empowerment, more likely to facilitate structural change.

Literature reviews for this study did not reveal another example of a PR study that had been systematically analysed via frameworks of power and empowerment in the way that this doctoral work has done. This study therefore contributes to knowledge by presenting a creative and in-depth approach to understanding the complex processes operating in PR, and using data in an original way.

The synthesis of models of empowerment, involvement and participation presented in Chapter Three is also a valuable contribution to knowledge as it demonstrates the way in which the forms of involvement and participation undertaken are likely to influence the nature of empowerment processes operating. Such explicit links between these models could not be identified in previous publications on this subject.

The models of involvement and participation reviewed are also of relevance to PR, in that PR theory implies democratic forms of involvement and participation where service users have influence and control over the agenda to achieve changes in their lives as a whole. Again, the literature is less clear on what strategies might be adopted in order to effect such large-scale change. This dissertation therefore highlights that any work carried out to explore strategies to achieve structural change would contribute to further developing and operationalising the democratic models of involvement and participation proposed by authors such as Croft and Beresford (1993).

The extent to which PR methodological principles can be adhered to in research with mental health service users, and issues for PR methodological development

This doctoral study has demonstrated that it is possible and beneficial to adopt a PR approach with mental health service users based upon the extensive PR literature, which originates from the work of Freire and fellow adult educators, critical theorists and feminist researchers. This work has an explicit value base concerned with oppressed people challenging their position in society and being acknowledged as self-determining agents capable of finding solutions to their own problems, with researchers supporting this political stance via facilitation and skills development rather than imposition of an externally-defined agenda.

Such work was very limited in the UK at the time of undertaking our project, and while 'user involvement' in research is now increasingly advocated by government and statutory organisations, this work is not necessarily underpinned by a similar value base and located within an emancipatory research paradigm. This doctoral work therefore contributes to knowledge advancement by presenting the successful implementation of a theoretically informed and politically motivated version of PR with British mental health service users.

It is hoped that this project will encourage other people, particularly mental health service users, to consider using similar forms of PR as an anti-oppressive and empowering methodology for undertaking research. It is also suggested that this doctoral work could usefully inform debates within the disability literature on ER, which often ignores the literature from the well-established tradition of PR as an emancipatory methodology.

In order to meet the research aim of considering the extent to which PR methodological principles could be adhered to in practice, I used our PR project to test this methodology by systematically and critically analysing PR processes operating during each project phase. Such systematic analysis was made possible by the structured analysis framework that I applied to the full range of data sources (see p.207-209). This approach produced a more rigorous analysis of PR processes operating than was previously available in the literature, and as such represents an

original contribution to knowledge advancement by providing a successful example of a structured analysis approach to data generated via PR.

At the time of embarking upon these doctoral studies, there was very little identifiable literature on PR with people experiencing mental distress. Interest in PR work with this group has grown, yet such work is still rarely found in 'mainstream' academic sources (Lindow, 2002). This project therefore makes an important contribution to this growing body of literature, as it demonstrates that PR is possible and beneficial with this oppressed group and provides a practical example of how such a project might progress (and potential constraints and tensions involved).

I was unable to identify in the literature any existing PR models of work with mental health service users, and therefore used Maguire's (1987) framework to structure the design of this doctoral project. This lack of 'precedents' within the literature gave me the challenge of new opportunities to be creative and innovative in my research work. On the basis of our experience, I have creatively adapted and developed this PR framework for use with the co-researchers involved, thereby making an original contribution to the development of PR methodology.

In addition to methodological development in the form of building upon an existing PR framework, and establishing a structured approach to data analysis, further areas for methodological development are proposed as a result of the experiences in our PR project. It is suggested that PR's potential as a strategy for empowerment could be further enhanced by having a more explicit strengths-focused emphasis from the outset, rather than a wholly negative focus on problems (as suggested by Maguire's framework). Identifying 'phases' within PR projects should only be used as a guiding structure, and should not act to 'close down' opportunities for further work within each phase if co-researchers so desire.

Action was a vitally important part of our PR project, not least as it resulted in material benefits for co-researchers for the time that they had invested in the research. It is therefore asserted that all PR projects should attempt to ensure that action results from the research, although it should also be emphasised from the outset that any action might take time to yield results (to avoid creating unrealistic expectations).

PR's rather simplistic 'zero-sum' conceptualisation of power, as something that the external researcher should 'hand over' to co-researchers, could be further developed (in line with the comprehensive theory of power proposed earlier) to acknowledge the complexity of power relations likely to be operating in any PR project, including between co-researchers themselves and between co-researchers and external agencies or professionals.

The tensions inherent in undertaking PR as a doctoral project have been highlighted (see p.345-346), and it is therefore suggested that if PR is undertaken for such purposes, the boundaries of the research student's involvement should be clearly stated from the start and co-researchers should be made aware of the constraints and requirements that the research student's role is likely to place on the project (for example, the need for final evaluation interviews, the need to have a clear 'end date', and the importance of public dissemination of the work). Similarly, if a PR project is located within a 'host organisation', very clear boundaries should be established with this organisation from the outset and reinforced throughout the project, to minimise possibilities of co-optation of the group's work for the organisation's own interests.

My experience of being involved in PR has also reinforced the need for participatory researchers to have strong groupwork skills, listening skills, and interpersonal skills. Training for participatory researchers (including co-researchers) should be available, which emphasises not only the theory and methodology underpinning PR but also the possible practical difficulties and corresponding skills likely to be required.

From our experience, ways in which our PR project might have been improved to maximise its impact and benefits to co-researchers included: working with a bigger group of people to maintain momentum and ensure adequate numbers of co-researchers were involved in taking decisions; explicitly addressing and revisiting issues of equal opportunity and valuing diversity throughout the project; working for a longer period with the group, as our action was about to yield results when the group ended; and building stronger links with other community groups to maximise the

likelihood of the work continuing and being developed[181]. These are important learning points in relation to the practice of PR, and as such contribute to the existing body of knowledge in this field.

This section has therefore demonstrated that this doctoral work has made original contributions to knowledge advancement in several ways, including undertaking original in-depth empirical work and critical synthesis of concepts and empirical evidence, development of PR methodology and its application in a new context, the testing of existing knowledge and theory in innovative ways, and development of a structured approach to data analysis in PR.

It is also important to outline the contributions that the findings of this doctoral work might make to the development of research, policy and practice in this area.

Implications for research

Since I began this doctoral work in 1996, there has been a significant proliferation of work to involve service users in research (in both voluntary and statutory sectors)[182], underpinned by a considerable national policy push (Consumers in Research, 1999; Department of Health, 2001b, 2002a). Nonetheless, I share the concerns of several mental health commentators that much of this work, particularly that within the statutory sector and initiated as a result of government 'requirements' to involve users, risks the dangers of co-optation, particularly if it is 'mainstreamed' (Rose, 2002) and underpinned with consumerist rather than democratic notions of involvement and participation (Beresford, 2002b). If such work is driven by consumerist aims of enhancing service delivery, rather than by political awareness of the benefits for people of involving them in a process from which they were previously marginalised, it is unlikely to contribute to countering oppression and facilitating liberational forms of empowerment.

---

[181] Our project was relatively 'staff-dependent' in that it relied to a large extent upon Sue taking forward the work within the host organisation. When Sue left the organisation, the likelihood of the group's work continuing was therefore significantly reduced.

[182] As of July 2004, over 40 mental health research projects are listed on INVOLVE's database of projects involving users in at least some stage of the research process.

Similar to user involvement in service planning and delivery, dangers of tokenism also exist, with user involvement in research being viewed as a 'box' to be 'ticked' on research proposals (Rose, 2002) rather than as a strategy for achieving change and improving conditions for mental health service users (Morris and Faulkner, 2002).

Nonetheless, developments in involving service users in research clearly represent a major potential culture change in terms of which groups are seen as legitimate producers of knowledge (Foucault, 1980), and as such are an important window of opportunity for service users to take greater control of research agendas, funding and processes. It is hoped that this doctoral work has both made a persuasive case for using research as a strategy for countering oppression and facilitating empowerment, and provided an example of a successful PR project with liberatory, democratic aims of involvement and empowerment concerned with enhancing mental health service users' rights to control their own lives. It is important to obtain a higher profile for such work, both to demonstrate its feasibility, and to emphasise its grounding in an anti-oppressive, empowering value base.

It is only by more service users undertaking and disseminating such 'political' work (either with other service users or in collaboration with researchers or practitioners as allies and resources) that the dangers of co-optation for agency purposes and corresponding dilution of the research's underpinning philosophy are likely be avoided. The growth of networks of mental health service users involved in research[183] and in national user-led research projects[184] suggests that this hope is being realised. Such networks and projects are also encouraging the development of training for service users in how to undertake research, an important element of capacity-building for mental health service users wishing to engage in such work (Rose, 2003).

---

[183] Such networks include the Survivor Researchers Network (Beresford, 2002b), Folk.us (The Forum for Collaboration with Users in Research) in South West England, and SURESearch, in the West Midlands.
[184] Examples of user-led research projects include the Sainsbury Centre for Mental Health's 'Users' Voices' Project (Rose D., 2001b), and the Mental Health Foundation's 'Strategies for Living' Project (Mental Health Foundation, 1997; Nicholls, 2001).

It is also argued that while PR might not succeed in fully reversing the social relations of research production, it can nonetheless be a useful starting point in facilitating processes of participation and empowerment via research for service users unaccustomed to being involved in such activities, due to the resources and infrastructure provided by the 'external' researcher. As such, learning from the PR project undertaken can contribute to the further development of PR methodology and practice with mental health service users, an important contribution to knowledge in that there are still only limited numbers of publications which discuss such issues in detail. It is acknowledged that PR is context-specific, and that its nature will change depending on the people involved, but the processes highlighted are likely to be similar and can therefore helpfully inform other people's research.

It is also contended that this doctoral work has demonstrated the benefits of becoming involved in PR for people using mental health services but not (yet) involved with the mental health user/survivor movement. While it is acknowledged that accessing people in this situation becomes more difficult, and often involves a 'gate-keeping' organisation (with the corresponding constraints and tensions, as discussed on p.347), it is nonetheless important to ensure that such potentially empowering opportunities are available to as wide a range of people with experience of mental distress as possible (and not only those already 'politicised' and active within the user/survivor movement).

With regard to the way in which research agendas are currently decided (and therefore considerable resources allocated), there is again increasing policy emphasis on enabling service users to have a voice in the way these agendas are set (e.g. Consumers in NHS Research, 1999; Department of Health, 2002a). In our project, the issues which co-researchers wanted to research were those relating to the material conditions of their lives, namely mobility and benefits, rather than 'medical' issues of 'treatment' or 'prognosis'. This illustrates the importance of ensuring that mental health service users are enabled to play a primary role in setting mental health research agendas, to facilitate the "reactivation of local knowledges... in opposition to the scientific hierarchisation of knowledges and the effects intrinsic to their power" (Foucault, 1980:85) and to ensure that issues considered important by mental health service users are addressed. Such recognition would also contribute to the reversal of

both social and material relations of mental health research production, similar to that advocated by disability writers (Oliver, 1992; Zarb, 1992).

The issue of ethical approval in research is becoming increasingly highlighted, as government policy develops to place significant safeguards (and potential constraints) on research undertaken with people using health and social care services (Department of Health, 2001b). Traditionally, ethical approval procedures have been very much geared towards the kind of positivist, experimental research discussed in Chapter Five, and researchers working within alternative paradigms using qualitative methods have struggled to 'fit' their proposals into such procedures. This issue is likely to be of equal or even greater concern for participatory and user-led research, with which ethics committees (comprised largely of medical practitioners) are unlikely to be familiar. For example, issues such as 'validity' and 'reliability', upon which much emphasis is placed within positivist research, are interpreted very differently in PR (see p.173-174).

It is therefore imperative that the current emphasis on encouraging user-led research is accompanied by guidance for both researchers (including user researchers) and people involved in ethics committees on how to maximise and assess quality in such research (in the context of the paradigm within which it is based). Places for service users on ethics committees might also facilitate greater understanding of user-led, participative forms of research, and enable service users to play an active role in this decision-making process.

With regard to the development of concepts and theories via research, this study has attempted to clarify the nature of empowerment processes potentially operating via research and has proposed a way of evaluating such processes. There are few examples of such work in the literature, and it is therefore suggested that more research might usefully be undertaken to further understand the way in which processes of empowerment develop, and in particular the way in which processes of individual, group and community empowerment might link together.

Considerable work has been undertaken on empowering social work practice (see p.83 and p.175), and it is clear that research and practice can learn lessons from one another in this respect. The sharing of such lessons should therefore be viewed as important, via education, training, courses, publications, and other networking opportunities. Such sharing can only serve to strengthen the work being undertaken in order to counter the oppression of mental health service users in Britain on various fronts.

Policy implications

More encouraging developments are evident in relation to the current British government's mental health policy (see p.137-139). These developments demonstrate some recognition amongst national policy makers of issues of oppression and disempowerment discussed in this dissertation, and the corresponding need to develop strategies for liberational empowerment which aim to counter this oppression.

Nonetheless, this dissertation has highlighted key issues that have implications for the effective implementation of government policies. The government's published 'vision' for mental health services (Department of Health, 2001a) acknowledges the importance of mental health service users being enabled to claim full citizenship, and to have "real prospects of recovery... if they are supported by appropriate services, driven by the right values and attitudes" (p.24).

Nonetheless, subsequent reports, including the work on mental health and social exclusion (Office of the Deputy Prime Minister, 2004) and the NIMHE's (2004) strategic plan to tackle stigma and discrimination, continue to use the medical, pathologising discourse of "illness" and "people with mental health problems". A paradox is therefore apparent, as government policy increasingly acknowledges the social exclusion of mental health service users and yet continues to accept the medical model of 'mental illness' which directly contributes to this social exclusion.

It is clear from this study that discursive formations of 'mental illness' play a strong role in maintaining unequal power relations, and in reproducing and maintaining oppression. Therefore, it can be argued that policies and strategies for countering

oppression and facilitating empowerment can only be fully effective if the current medical constructions of 'mental illness' are challenged. In New Zealand, for example, all mental health services are now explicitly based on a recovery vision, with a corresponding shift in emphasis from 'illness' to rights and self-determination (Lapsley et al, 2002; Turner, 2001). Evidence from work undertaken for this dissertation suggests that until such a shift in conceptualising distress occurs amongst British policy makers and practitioners, as already advocated strongly by the mental health user/survivor movement, any strategies for empowerment will be diluted by the continuing predominance of the medical model of 'mental illness' and its extremely damaging consequences for people using mental health services (see p.15-18).

Another contradictory element of government policy in relation to mental health service users already highlighted in this dissertation (p.139-140) is its emphasis on improving citizenship and combating discrimination and social exclusion while simultaneously attempting to introduce even more restrictive mental health legislation (Department of Health, 1999d, 2002b; Department of Health and Home Office, 2000) which would serve to further constrain mental health service users' rights and to increase public misperceptions of the 'dangerousness' of people in mental distress.

Recognition of the importance of social models of distress is occurring in some government agencies (see p.138-139). Moves in psychiatry to align more closely with a social model of distress are less evident, perhaps unsurprisingly given the serious challenges to its power base and legitimacy which such an alignment would entail. However, it is clear that if the British government intends to 'deliver' on its aims to reduce social exclusion and discrimination outlined in the ODPM's (2004) report, and thereby counter mental health service users' oppression, more 'harmonisation' of policies is required, giving increased recognition to social models of distress and corresponding models of empowerment and recovery, and placing less emphasis on disciplinary power and coercive treatment of mental health service users.

This dissertation has also highlighted the various levels and dimensions on which both oppression and power operate. Such theory can usefully be applied to the potential success of policy implementation in this regard, in that it is clear that policies must aim to tackle all of these levels and dimensions in order to be effective in countering oppression and discrimination, due to their interconnectedness.

Practice implications

Finally, in recognition of the finding from our research that people in mental distress continue to seek the support of mental health services to deal with this distress, some implications for service development were clear from fieldwork data obtained in our PR project.

Material conditions, such as transport and benefit levels, were clearly an issue of major importance for the quality of life of co-researchers, and indeed were the subjects on which they chose to take action. As material conditions have been identified as prerequisites for empowerment (Nelson et al, 1998), it is clear that health and social care professionals committed to empowering practice with mental health service users need to look beyond supporting people to recover from their distress to consider how they can enable improvements in people's material conditions by accessing resources and linking with other relevant agencies.

Some specific points in relation to service provision emerged from our PR project, which have implications for practice. For example, most co-researchers in our project expressed a strong fear or dislike of being in psychiatric hospital yet also a clear desire for both emergency and ongoing support from health and social care services in the community (see p.226-228, for example). This theme emerged repeatedly in our research, and supports policy moves to develop 24-hour services and community 'emergency houses' to avert hospital admissions. Plans to develop more integrated care planning systems are also likely to benefit people using mental health services, in ensuring that valued support continues to be available after discharge from hospital.

A striking issue highlighted in our research was co-researchers' anxieties about being 'deprived' of mental health services and being 'made' to be more independent and use mainstream services (discussed on p.285-286, for example). Such suggestions raised fears and anxieties for co-researchers, many of whom had become accustomed to 'safe' institutionalised activities involving only other mental health service users. While it is acknowledged that such moves to encourage people to access mainstream facilities are an important element of encouraging social inclusion, it is critical that any such moves are negotiated and agreed with service users themselves if they are to be perceived as beneficial rather than punitive by service users. It was clear from co-researchers' comments that 'independence' should not be taken to mean having to manage without valued health and social care services, but should be more concerned with people being allowed space to change and grow, taking control to live their lives in the way that they choose (Morris, 1997) (which may involve continuing help and support from mental health services).

All of the co-researchers' comments on service provision highlight the importance of involving service users not only in research but also in service planning, development and delivery, to ensure that such services fully meet the expressed needs of service users rather than those of planners and service providers. To enable service users to have a strong and active role rather than a token input, such involvement should be towards the maximum end of Philpot's (1994) continuum (see p.99).

Final reflections

There is an ever growing interest in and emphasis on the empowerment and emancipation of oppressed groups, including mental health service users, and therefore increasing interest in the potential of research as an empowering strategy for people with experience of mental distress. This dissertation has demonstrated that PR can facilitate processes of individual and group empowerment, and may therefore be a first step towards the longer-term and far more ambitious goal of achieving broader, liberational empowerment via social action and change to counter structural oppression.

This latter goal is likely to be best achieved by combining research with other strategies for empowerment such as collective action, campaigning and lobbying, and by joining together with other oppressed groups with common interests, such as the disability movement. Government policy could be used to further develop these strategies, but is only likely to be fully supportive of such work if it acknowledges the oppressive nature of the medical model of 'mental illness' which it currently endorses and perpetuates, and commits to supporting social approaches to understanding and dealing with distress advocated by the mental health user/survivor movement.

Bibliography

Abberley, P. (1987) The concept of oppression and the development of a social theory of disability. *Disability, Handicap and Society*. 2(1), 5-19.

Abbott, P. & Wallace, C. (1990) The sociology of the caring professions: an introduction. In P. Abbott & C. Wallace (eds.), *The Sociology of the Caring Professions* (pp. 1-9). London: Falmer Press.

Adams, R. (1996) *Social Work and Empowerment* (2nd ed.). Basingstoke: Macmillan.

Adams, R. (1998) Strategies of empowerment: taking account of protests by people. In B. Lesnik (ed.), *Countering Discrimination in Social Work* (pp. 133-163). Aldershot: Ashgate Arena.

Adams, R. (2003) *Social Work and Empowerment* (3rd ed.). Basingstoke: Palgrave Macmillan.

Adler, M. & Asquith, S. (1993) Discretion and power. In M. Hill (ed.), *The Policy Process: A reader* (pp. 399-406). Hemel Hempstead: Harvester Wheatsheaf.

Allott, P. and Loganathan, L. (2002) *Discovering Hope for Recovery from a British Perspective – A review of a sample of recovery literature, implications for practice and systems change.* Birmingham: West Midlands Partnerships for Mental Health.

Alverson, M., Becker, D. R. & Drake, R. E. (1995) An ethnographic study of coping strategies used by people with severe mental illness participating in supported employment. *Psychosocial Rehabilitation Journal*. 18(4), 115-128.

Anderson, J. M. (1996) Empowering patients: issues and strategies. *Social Science and Medicine*. 43(5), 697-705.

Armstrong, D. (1990) Medicine as a profession: times of change. *British Medical Journal*. 301, 691-693.

Arnstein, S. R. (1969) A ladder of citizen participation. *Journal of the American Institute of Planners*. 35(4), 216-224.

Arscott, K. (1999) ECT: the facts psychiatry declines to mention. In C. Newnes, G. Holmes & C. Dunn (eds.), *This is Madness: A critical look at psychiatry and the future of mental health services* (pp. 97-118). Ross-on-Wye: PCCS Books.

Atkinson, P. & Hammersley, M. (1998) Ethnography and participant observation. In N. K. Denzin & Y. S. Lincoln (eds.) *Strategies of Qualitative Inquiry* (pp. 110-136). Thousand Oaks, CA: Sage.

Atkinson, R. (1999) Discourses of partnership and empowerment in contemporary British urban regeneration. *Urban Studies*. 36(1), 59-72.

Atkinson, R. & Cope, S. (1997) Community participation and urban regeneration in Britain. In P. Hoggett (ed.), *Contested Communities: Experiences, struggles, policies* (pp. 201-221). Bristol: The Policy Press.

Babbie, E. (2001) *The Practice of Social Research* (9th ed.). Belmont, CA: Wadsworth/Thomson Learning.

Baistow, K. (1994) Liberation and regulation? Some paradoxes of empowerment. *Critical Social Policy*. 14(3), 34-46.

Baker, S. & Strong, S. (2001) *Roads to Recovery: How people with mental health problems recover and find ways of coping*. London: Mind.

Barham, P. (1997) *Closing the Asylum: The mental patient in modern society* (2nd ed.). London: Penguin.

Barham, P. & Hayward, R. (1996) The lives of 'users'. In T. Heller, J. Reynolds, R. Gomm, R. Muston & S. Pattison (eds.), *Mental Health Matters: A reader* (pp. 226-237). Basingstoke: Macmillan.

Barker, I. & Peck, E. (1987) Thinking it through: theoretical perspectives. In I. Barker & E. Peck (eds.), *Power in Strange Places: User empowerment in mental health services* (pp. 1-3). London: Good Practices in Mental Health.

Barker, J., Bullen, M. & de Ville, J. (1999) *Reference Manual for Public Involvement* (2nd ed.). Bromley Health, West Kent Health Authority and Lambeth, Southwark & Lewisham Health Authority.

Barnes, M. (1997a) *Care, Communities and Citizens*. London: Longman.

Barnes, M. (1997b) Families and empowerment. In P. Ramcharan, G. Roberts, G. Grant & J. Borland (eds.), *Empowerment in Everyday Life: Learning disability* (pp. 70-87). London: Jessica Kingsley.

Barnes, M. (1999a) Users as citizens: collective action and the local governance of welfare. *Social Policy and Administration*. 33(1), 73-90.

Barnes, M. (1999b) Working with older people to evaluate the Fife User Panels Project. In M. Barnes & L. Warren (eds.), *Paths to Empowerment* (pp. 107-118). Bristol: The Policy Press.

Barnes, M. & Bowl, R. (2001) *Taking Over the Asylum: Empowerment and mental health*. Basingstoke: Palgrave.

Barnes, M. & Prior, D. (1996) From private choice to public trust: a new social basis for welfare. *Public Money and Management*. October-December, 51-57.

Barnes, M. & Shardlow, P. (1997) From passive recipient to active citizen: participation in mental health user groups. *Journal of Mental Health*. 6(3), 289-300.

Barnes, M. & Walker, A. (1996) Consumerism versus empowerment: a principled approach to the involvement of older service users. *Policy and Politics*. 24(4), 375-393.

Barnes, M. & Warren, L. (1999) Introduction to Part Two. In M. Barnes & L. Warren (eds.), *Paths to Empowerment* (pp. 70-74). Bristol: The Policy Press.

Barnes, M. & Wistow, G. (1994) Learning to hear voices: listening to users of mental health services. *Journal of Mental Health*. 3, 525-540.

Barnes, M., Davis, A. & Rogers, H. (2002) Towards women-sensitive mental health services. *The Mental Health Review*. 7(1), 19-21.

Barnes, M., Davis, A. & Tew, J. (2000) Valuing experience: users' experiences of compulsion under the Mental Health Act 1983. *The Mental Health Review*. 5(3), 11-14.

Barnes, M., Harrison, S., Mort, M. & Shardlow, P. (1999) *Unequal Partners: User groups and community care*. Bristol: The Policy Press.

Batsleer, J. (1995) Management and organisation. In J. D. Smith, C. Rochester & R. Hedley (eds.) *An Introduction to the Voluntary Sector* (pp. 224-248). London: Routledge.

Beeforth, M. (1993) Users are people. In V. Williamson (ed.), *Users First: The real challenge for community care* (pp. 19-28). Brighton: University of Brighton.

Beeforth, M., Conlan, E., Field, V., Hoser, B. & Sayce, L. (1990) *Whose Service is it Anyway? Users' views on co-ordinating community care*. London: Research and Development for Psychiatry.

Bell, E. E. (2001) Infusing race into the US discourse on action research. In P. Reason & H. Bradbury (eds.), *Handbook of Action Research: Participative inquiry and practice* (pp. 48-58). London: Sage.

Beresford, P. (1997) Identity, structures, services and user involvement. *Research Policy and Planning*. 15(2), 5-9.

Beresford, P. (2000) What have madness and psychiatric system survivors got to do with disability and disability studies? *Disability and Society*. 15(1), 167-172.

Beresford, P. (2001a) Service users, social policy and the future of welfare. *Critical Social Policy*. 21(4), 494-512.

Beresford, P. (2001b) User involvement and social care research. *Consumers in NHS Research Support Unit News*. Summer, 4.

Beresford, P. (2002a) Thinking about 'mental health': towards a social model. *Journal of Mental Health*. 11(6), 581-584.

Beresford, P. (2002b) User involvement in research and evaluation: liberation or regulation? *Social Policy and Society*. 1(2), 95-105.

Beresford, P. & Croft, S. (1993) *Citizen Involvement: A practical guide for change.* Basingstoke: Macmillan.

Beresford, P. & Evans, C. (1999) Research note: research and empowerment. *British Journal of Social Work.* 29, 671-677.

Beresford, P. & Trevillion, S. (1995) *Developing Skills for Community Care: A collaborative approach.* Aldershot: Arena.

Beresford, P. & Wallcraft, J. (1997) Psychiatric system survivors and emancipatory research: issues, overlaps and differences. In C. Barnes & G. Mercer (eds.), *Doing Disability Research* (pp. 67-87). Leeds: The Disability Press.

Beresford, P. & Wilson, A. (2002) Genes spell danger: mental health service users/survivors, bioethics and control. *Disability and Society.* 17(5), 541-553.

Beresford, P., Croft, S., Evans, C. & Harding, T. (2000) Quality in personal social services: the developing role of user involvement in the UK. In C. Davies, L. Finlay & A. Bullman (eds.), *Changing Practice in Health and Social Care* (pp. 189-197). London: Sage/Open University Press.

Beresford, P., Gifford, G. & Harrison, C. (1996) What has disability got to do with psychiatric survivors? In J. Read & J. Reynolds (eds.), *Speaking Our Minds: An anthology of personal experiences of mental distress and its consequences* (pp. 209-214). Basingstoke: Macmillan.

Biehal, N. (1993) Changing practice: participation, rights and community care. *British Journal of Social Work.* 23, 443-458.

Billis, D. (1993) *Organising Public and Voluntary Agencies.* London: Routledge.

Boje, D. M. & Rosile, G. A. (2001) Where's the power in empowerment? Answers from Follett and Clegg. *Journal of Applied Behavioral Science.* 37(1), 90-117.

Bowl, R. (1996) Involving service users in mental health services: Social Services Departments and the National Health Service and Community Care Act 1990. *Journal of Mental Health.* 5(3), 287-303.

Boyle, M. (1999) Diagnosis. In C. Newnes, G. Holmes & C. Dunn (eds.), *This is Madness: A critical look at psychiatry and the future of mental health services* (pp. 75-90). Ross-on-Wye: PCCS Books.

Brackx, A. (1989) Introduction. In A. Brackx & C. Grimshaw (eds.), *Mental Health Care in Crisis* (pp. 1-8). London: Pluto Publishing.

Bradley, J. E., Mayfield, M. V., Mehta, M. P. & Rukonge, A. (2002) Participatory evaluation of reproductive health care quality in developing countries. *Social Science and Medicine.* 55, 269-282.

Brandon, D. (1991) *Innovation Without Change? Consumer power in psychiatric services.* Basingstoke: Macmillan.

Brandon, D. (1995a) Peer support and advocacy - international comparisons and developments. In R. Jack (ed.), *Empowerment in Community Care* (pp. 108-133). London: Chapman & Hall.

Brandon, D. (1995b) *Advocacy: Power to people with disabilities*. Birmingham: Venture Press.

Braye, S. (2000) Participation and involvement in social care. In H. Kemshall & R. Littlechild (eds.), *User Involvement and Participation in Social Care: Research informing practice* (pp. 9-28). London: Jessica Kingsley.

Braye, S. & Preston-Shoot, M. (1995) *Empowering Practice in Social Care*. Buckingham: Open University Press.

Breggin, P. (1993) *Toxic Psychiatry*. London: Fontana.

Brewin, C. R. (1992) Believing what patients tell us. *Journal of Mental Health*. 1, 83-84.

Bricher, G. (2000) Disabled people, health professionals and the social model of disability: can there be a research relationship? *Disability and Society*. 15(5), 781-793.

Brindle, D. (1999) Firm admits mental illness job bias. *The Guardian*. 24th December, 2.

Brittan, A. & Maynard, M. (1984) *Sexism, Racism and Oppression*. Oxford: Blackwell.

Brown, A. (1997) Groupwork. In M. Davies (ed.) *The Blackwell Companion to Social Work* (pp. 223-230). Oxford: Blackwell.

Brown, G. W., & Harris, T. (1978) *Social Origins of Depression: A study of psychiatric disorder in women*. London: Tavistock Publications Ltd.

Browne, D. (1996) The Black experience of mental health law. In T. Heller, J. Reynolds, R. Gomm, R. Muston & S. Pattison (eds.), *Mental Health Matters: A reader* (pp. 196-204). Basingstoke: Macmillan.

Busfield, J. (1988) Mental illness as social product or social construct: a contradiction in feminists' arguments? *Sociology of Health and Illness*. 10, 521-542.

Busfield, J. (1996a) *Men, Women and Madness: Understanding gender and mental disorder*. Basingstoke: Macmillan.

Busfield, J. (1996b) Professionals, the state and the development of mental health policy. In T. Heller, J. Reynolds, R. Gomm, R. Muston & S. Pattison (eds.), *Mental Health Matters: A reader* (pp. 132-142). Basingstoke: Macmillan.

Busfield, J. (2000) Introduction: rethinking the sociology of mental health. *Sociology of Health and Illness*. 22(5), 543-558.

Calnan, M. & Gabe, J. (2001) From consumerism to partnership? Britain's National Health Service at the turn of the century. *International Journal of Health Services*. 31(1), 119-131.

Campbell, J. (2002) A critical appraisal of participatory methods in development research. *International Journal of Social Research Methodology*. 5(1), 19-29.

Campbell, P. & Lindow, V. (1997) *Changing Practice: Mental health nursing and user empowerment.* London: Royal College of Nursing/Mind.

Campbell, P. (1990) Mental health self-advocacy. In L. Winn (ed.), *Power to the People: The key to responsive services in health and social care* (pp. 69-78). London: King's Fund Centre.

Campbell, P. (1992) A survivor's view of community psychiatry. *Journal of Mental Health*. 1, 117-122.

Campbell, P. (1996) The history of the user movement in the United Kingdom. In T. Heller, J. Reynolds, R. Gomm, R. Muston & S. Pattison (eds.), *Mental Health Matters: A reader* (pp. 218-225). Basingstoke: Macmillan.

Campbell, P. (1999a) The future of the mental health system: a survivor's perspective. *Mental Health Practice*. 3(1), 12-17.

Campbell, P. (1999b) The service user/survivor movement. In C. Newnes, G. Holmes & C. Dunn (eds.), *This is Madness: A critical look at psychiatry and the future of mental health services* (pp. 195-209). Ross-on-Wye: PCCS Books.

Campbell, P. (2001) The role of users of psychiatric services in service development - influence not power. *Psychiatric Bulletin*. 25, 87-88.

Campbell, T. & Heginbotham, C. (1991) *Mental Illness: Prejudice, discrimination and the law*. Aldershot: Dartmouth.

Carr, V. (1988) Patients' techniques for coping with schizophrenia: An exploratory study. *British Journal of Medical Psychology*. 61, 339-352.

Carspecken, P. F. & Apple, M. (1992) Critical qualitative research: theory, methodology and practice. In M. LeCompte, W. L. Millroy & J. Preissle (eds.), *The Handbook of Qualitative Research in Education* (pp. 507-553). San Diego, CA: Academic Press.

Chamberlin, J. (1987) The case for separatism: ex-patient organising in the United States. In I. Barker & E. Peck (eds.), *Power in Strange Places: User empowerment in mental health services* (pp. 24-26). London: Good Practices in Mental Health.

Chamberlin, J. (1988) *On our Own: Patient-controlled alternatives to the mental health system* (UK ed.). London: Mind.

Chesler, P. (1974) *Women and Madness*. London: Allen Lane.

Christians, C. G. (2000) Ethics and politics in qualitative research. In N. K. Denzin & Y. S. Lincoln (eds.) *Handbook of Qualitative Research* (2nd ed., pp. 133-155). Thousand Oaks, CA: Sage.

Clare, A. (1980) *Psychiatry in Dissent: Controversial issues in thought and practice* (2nd ed.). London: Routledge.

Clarke, J. (1998) Doing the right thing? Managerialism and social welfare. In P. Abbott & L. Meerabeau (eds.), *The Sociology of the Professions* (2nd ed., pp. 234-254). London: UCL Press.

Clarke, J. & Newman, J. (1997) *The Managerial State: Power, politics and ideology in the remaking of social welfare.* London: Sage.

Clegg, S. (1989) *Frameworks of Power.* London: Sage.

Clough, R. (1990) *Practice, Politics and Power in Social Services Departments.* Aldershot: Avebury.

Cocks, E. & Cockram, J. (1995) The participatory research paradigm and intellectual disability. *Mental Handicap Research.* 8(1), 25-37.

Cocks, E. & Cockram, J. (1997) Empowerment and the limitations of formal human services and legislation. In P. Ramcharan, G. Roberts, G. Grant & J. Borland (eds.), *Empowerment in Everyday Life: Learning disability* (pp. 222-240). London: Jessica Kingsley.

Coleman, R. (1999a) Hearing voices and the politics of oppression. In C. Newnes, G. Holmes & C. Dunn (eds.), *This is Madness: A critical look at psychiatry and the future of mental health services* (pp. 149-164). Ross-on-Wye: PCCS Books.

Coleman, R. (1999b) *Recovery an Alien Concept?* Gloucester: Handsell Publishing.

Comer, R. J. (2001) *Abnormal Psychology* (4th ed.). New York: Worth Publishing.

Consumers in NHS Research (1999) *Research and Development in the NHS: How can you make a difference?* London: Department of Health.

Cooper, Z. & Cooper, P. J. (1988) Classification and diagnosis. In E. Miller & P. Cooper (eds.), *Adult Abnormal Psychology* (pp. 6-25). Edinburgh: Churchill Livingstone.

Cornwall, A. (1996) Towards participatory practice: participatory rural appraisal (PRA) and the participatory process. In K. de Koning & M. Martin (eds.), *Participatory Research in Health: Issues and experiences* (pp. 94-107). London: Zed Books.

Cornwall, A. & Jewkes, R. (1995) What is participatory research? *Social Science and Medicine.* 41(12), 1667-1676.

Corrigan, P. W. & Penn, D. (1997) Disease and discrimination: two paradigms that describe severe mental illness. *Journal of Mental Health*. 6(4), 355-366.

Cousins, M. & Hussain, A. (1984) *Michel Foucault*. New York: St Martin's Press.

Crawford, M. (2001) Involving users in the development of psychiatric services - no longer an option. *Psychiatric Bulletin*. 25, 84-86.

Creswell, J. W. (1998) *Qualitative Inquiry and Research Design: Choosing among five traditions*. Thousand Oaks, CA: Sage.

Crinson, I. (1998) Putting patients first: the continuity of the consumerist discourse in health policy, from the radical right to New Labour. *Critical Social Policy*. 18(2), 227-239.

Croft, S. & Beresford, P. (1993) *Getting Involved: A practical manual*. London: Open Services Project.

Croft, S. & Beresford, P. (1995) Whose empowerment? Equalizing the competing discourses in community care. In R. Jack (ed.), *Empowerment in Community Care* (pp. 59-73). London: Chapman & Hall.

Croft, S. & Beresford, P. (1996) The politics of participation. In D. Taylor (ed.), *Critical Social Policy A Reader: Social policy and social relations*. London: Sage.

Crotty, M. (1998) *The Foundations of Social Research: Meaning and perspective in the research process*. London: Sage.

Cryer, P. (1996) *The Research Student's Guide to Success*. Buckingham: Open University Press.

Curran, T. (1997) Power, participation and post modernism: user and practitioner participation in mental health social work education. *Social Work Education*. 16(3), 21-36.

Curtis, L. (1997) *New Directions: International overview of best practices in recovery and rehabilitation services for people with serious mental illness - a discussion paper*. Wellington: Mental Health Commission.

Dalrymple, J. & Burke, B. (1995) *Anti-Oppressive Practice: Social care and the law*. Buckingham: Open University Press.

Davey, B. (1999) Solving economic, social and environmental problems together: an empowerment strategy for losers. In M. Barnes & L. Warren (eds.), *Paths to Empowerment* (pp. 37-49). Bristol: The Policy Press.

David, M. (2002) Problems of participation: the limits of action research. *International Journal of Social Research Methodology*. 5(1), 11-17.

Davidson, J. O. & Layder, D. (1994) *Methods, Sex and Madness*. London: Routledge.

Davies, C. (1996) The sociology of professions and the profession of gender. *Sociology*. 30(4), 661-678.

Davis, A. (1984) Day care. In M. R. Olsen (ed.) *Social Work and Mental Health: A guide for the Approved Social Worker* (pp. 129-137). London: Tavistock.

Davis, A. (2003) Still not good enough. *Openmind*. 123, 26-27.

Davis, A. & Bird, L. (2001) Getting to the root. *Openmind*. 110, 12-13.

Davis, A., Llewelyn, S. & Parry, G. (1985) Women and mental health: towards an understanding. In E. Brook & A. Davis (eds.), *Women, The Family and Social Work* (pp. 70-91). London: Tavistock Publications.

Davis, H. (1996) Psychodynamics and empowerment in community mental health. *Journal of Social Work Practice*. 10(2), 157-162.

Davis, J. M. (2000) Disability studies as ethnographic research and text: research strategies and roles for promoting social change? *Disability and Society*. 15(2), 191-206.

Davis, S. (2002) Autonomy versus coercion: reconciling competing perspectives in community mental health. *Community Mental Health Journal*. 38(3), 239-250.

Davison, G. C. & Neale, J. M. (2001) *Abnormal Psychology* (8th ed.). New York: John Wiley & Sons.

de Koning, K. & Martin, M. (1996a) Participatory research in health: setting the context. In K. de Koning & M. Martin (eds.), *Participatory Research in Health: Issues and experiences* (pp. 1-18). London: Zed Books.

de Koning, K. & Martin, M. (1996b) *Participatory Research in Health: Issues and experiences*. London: Zed Books.

Deegan, P. (1996) Recovery as a journey of the heart. *Psychiatric Rehabilitation Journal*. 19(3), 91-97.

Deegan, P. (1997) Recovery and empowerment for people with psychiatric disabilities. *Social Work in Health Care*. 25(3), 11-24.

Denzin, N. K. (1994) The art and politics of interpretation. In N. K. Denzin & Y. S. Lincoln (eds.), *Handbook of Qualitative Research* (pp. 500-515). Thousand Oaks, CA: Sage.

Denzin, N. K. & Lincoln, Y. S. (1998) Introduction: Entering the field of qualitative research. In N. K. Denzin & Y. S. Lincoln (eds.), *Strategies of Qualitative Inquiry* (pp. 1-34). Thousand Oaks, CA: Sage.

Department of Health (1989) *Working for Patients*. London: Department of Health.

Department of Health (1992) *Local Voices: The views of local people in purchasing for health*. London: Department of Health.

Department of Health (1996a) *The Patient's Charter: Mental health services*. London: Department of Health.

Department of Health (1996b) *Building Bridges: A guide to arrangements for inter-agency working for the care and protection of severely mentally ill people*. London: Department of Health.

Department of Health (1997) *The New NHS: Modern, dependable*. London: Department of Health.

Department of Health (1998) *Modernising Mental Health Services: Safe, sound and supportive*. London: Department of Health.

Department of Health (1999a) *Saving Lives: Our healthier nation*. London: The Stationery Office.

Department of Health (1999b) *Patient and Public Involvement in the New NHS*. London: Department of Health.

Department of Health (1999c) *National Service Framework for Mental Health: Modern standards and service models*. London: Department of Health.

Department of Health (1999d) *Reform of the Mental Health Act 1983: Proposals for consultation*. London: The Stationery Office.

Department of Health (2000a) *The NHS Plan: A plan for investment, a plan for reform*. London: The Stationery Office.

Department of Health (2000b) *The Government's Response to the Health Select Committee's Report into Mental Health Services*. London: The Stationery Office.

Department of Health (2001a) *The Journey to Recovery - The Government's vision for mental health care*. London: Department of Health.

Department of Health (2001b) *Research Governance Framework for Health and Social Care*. London: Department of Health.

Department of Health (2002a) *The National Institute for Mental Health in England (NIMHE): Establishing the Mental Health Research Network*. London: Department of Health.

Department of Health (2002b) *Mental Health Bill Consultation Document*. London: The Stationery Office.

Department of Health (2002c) *Women's Mental Health: Into the mainstream. Strategic development of mental health care for women*. London: Department of Health.

Department of Health and Home Office (2000) *Reforming the Mental Health Act Part I: The new legal framework.* London: The Stationery Office.

Department of the Environment, Transport and the Regions (1998) *Modernising Local Government: Improving local services through Best Value.* London: The Stationery Office.

Deyhle, D. L., Hess Jr., A. & LeCompte, M. D. (1992) Approaching ethical issues for qualitative researchers in education. In M. D. LeCompte, W. L. Millroy & J. Preissle (eds.) *The Handbook of Qualitative Research in Education* (pp. 597-641). San Diego, CA: Academic Press.

Dickerson, F. B. (1998) Strategies that foster empowerment. *Cognitive and Behavioral Practice.* 5, 255-275.

Dockery, G. (2000) Participatory research: whose roles, whose responsibilities? In C. Truman, D. M. Mertens & B. Humphries (eds.), *Research and Inequality* (pp. 95-110). London: UCL Press.

Dodd, T. (1998) The social construction of the mental health service user. *Mental Health Practice.* 8(6), 21-26.

Dohrenwend, B. P. (1990) Socioeconomic status (SES) and psychiatric disorders: Are the issues still compelling? *Social Psychiatry and Psychiatric Epidemiology.* 25, 41-47.

Dominelli, L. (2002) *Anti-Oppressive Social Work Theory and Practice.* Basingstoke: Palgrave Macmillan.

Donlan, P. (1993) Empowerment and quality in community care. In V. Williamson (ed.), *Users First: The real challenge for community care* (pp. 29-36). Brighton: University of Brighton.

Dowson, S. (1997) Empowerment within services: a comfortable delusion. In P. Ramcharan, G. Roberts, G. Grant & J. Borland (eds.), *Empowerment in Everyday Life: Learning disability* (pp. 101-120). London: Jessica Kingsley.

Driver, F. (1994) Bodies in space: Foucault's account of disciplinary power. In C. Jones & R. Porter (eds.), *Reassessing Foucault: Power, medicine and the body* (pp. 113-131). London: Routledge.

Duckett, P. (1998) What are you doing here? 'Non disabled' people and the disability movement: a response to Fran Branfield. *Disability and Society.* 13(4), 625-628.

Dullea, K. & Mullender, A. (1999) Evaluation and empowerment. In I. Shaw & J. Lishman (eds.), *Evaluation and Social Work Practice* (pp. 81-100). London: Sage.

Dunn, S. (1999) *Creating Accepting Communities: Report of the Mind inquiry into social exclusion and mental health problems.* London: Mind.

Eichler, M. (1988) *Nonsexist Research Methods: A practical guide.* Boston: Allen & Unwin.

Ekpe, H. (2001) Empowerment for adults with chronic mental health problems and obesity. *Nursing Standard.* 15(39), 37-42.

Ellis, K. (2000) User involvement, community care and disability research. In H. Kemshall & R. Littlechild (eds.), *User Involvement and Participation in Social Care: Research informing practice* (pp. 215-231). London: Jessica Kingsley.

Ellis, P. (1990) Participatory research methodology and process: experience and perspective of a Caribbean researcher. *Convergence.* 23(4), 23-34.

Evans, C. (1996) Service users acting as agents of change. In P. Bywaters & E. McLeod (eds.), *Working for Equality in Health.* London: Routledge.

Evans, C. & Fisher, M. (1999) Collaborative evaluation with service users: moving towards user-controlled research. In I. Shaw & J. Lishman (eds.), *Evaluation and Social Work Practice* (pp. 101-117). London: Sage.

Evans, E. N. (1992) Liberation theology, empowerment theory and social work practice with the oppressed. *International Social Work.* 35(2), 135-147.

Everitt, A., Hardiker, P., Littlewood, J. & Mullender, A. (1992) *Applied Research for Better Practice.* Basingstoke: Macmillan.

Exell, J. & Mayes, D. (2003) Who needs a day centre? *Openmind.* 120, 26.

Exworthy, M. & Halford, S. (1999) Professionals and managers in a changing public sector: conflict, compromise and collaboration? In M. Exworthy & S. Halford (eds.), *Professionals and the New Managerialism in the Public Sector* (pp. 1-17). Buckingham: Open University Press.

Fals Borda, O. (2001) Participatory (action) research in social theory: origins and challenges. In P. Reason & H. Bradbury (eds.), *Handbook of Action Research: Participative inquiry and practice* (pp. 27-37). London: Sage.

Fawcett, B. & Hearn, J. (2001) Research and 'disability': accounts, biographies and policies. *Research Policy and Planning.* 19(2), 27-36.

Ferguson, I. (1997) The impact of mental health user involvement. *Research Policy and Planning.* 15(2), 26-30.

Fernando, S. (1995) Social realities and mental health. In S. Fernando (ed.), *Mental Health in a Multi-Ethnic Society: A multi-disciplinary handbook* (pp. 11-35). London: Routledge.

Fernando, S. (2002) *Mental Health, Race and Culture* (2nd ed.). Basingstoke: Palgrave.

Fetterman, D. M. (2000) *Foundations of Empowerment Evaluation*. Thousand Oaks, CA: Sage.

Fine, M., Boudin, K., Bowen, I., Clark, J., Hylton, D., Martinez, M., Missy, Rivera, M., Roberts, R. A., Smart, P., Torre, M. E. & Upegui, D. (2001) Participatory action research: from within and beyond prison bars. *Bridging the Gap: Feminisms and Participatory Action Research Conference,* 22nd-24th June, Boston.

Finkelstein, V. (1999) Extended review: Doing Disability Research. *Disability and Society*. 14(6), 859-867.

Finn, J. (1994) The promise of participatory research. *Journal of Progressive Human Services*. 5(2), 25-42.

Fitzsimons, S. & Fuller, R. (2002) Empowerment and its implications for clinical practice in mental health: a review. *Journal of Mental Health*. 11(5), 481-499.

Fleming, B. & Golding, L. (1997) *Involving Users: Volume 1*. Birmingham: Soundings Research.

Flick, U. (2002) *An Introduction to Qualitative Research* (2nd ed.). London: Sage.

Flynn, R. (1999) Managerialism, professionalism and quasi-markets. In M. Exworthy & S. Halford (eds.), *Professionals and the New Managerialism in the Public Sector* (pp. 18-36). Buckingham: Open University Press.

Fontana, A. & Frey, J. H. (1998) Interviewing: the art of science. In N. K. Denzin & Y. S. Lincoln (eds.) *Collecting and Interpreting Qualitative Materials* (pp. 47-78). Thousand Oaks, CA: Sage.

Fook, J. (2002) *Social Work: Critical theory and practice.* London: Sage.

Forrest, D. (2000) Theorising empowerment thought: illuminating the relationship between ideology and politics in the contemporary era. *Sociological Research Online*. 4(4).

Foster, P. & Wilding, P. (2000) Whither welfare professionalism? *Social Policy and Administration*. 34(2), 143-159.

Foucault, M. (1977) *Discipline and Punish: The birth of the prison*. London: Allen Lane.

Foucault, M. (1980) *Power/Knowledge: Selected interviews and other writings 1972-1977*. Hemel Hempstead: Harvester Wheatsheaf.

Foucault, M. (1983) Afterword: The subject and power. In H. L. Dreyfus & P. Rabinow, *Michel Foucault: Beyond structuralism and hermeneutics* (2nd ed., pp. 208-226). Chicago: The University of Chicago Press.

Foucault, M. (1989) *The Birth of the Clinic: An archaeology of medical perception.* London: Routledge.

Foucault, M. (1998) *The Will to Knowledge: The History of Sexuality Volume One* (Penguin ed.). London: Penguin.

Fraher, A. & Limpinnian, M. (1999) User empowerment within mental health nursing. In G. Wilkinson & M. Miers (eds.), *Power and Nursing Practice* (pp. 144-157). Basingstoke: Macmillan.

Frankel, B. (1982) On participant-observation as a component of evaluation. *Evaluation and Program Planning.* 5, 239-246.

Frankland, J. & Bloor, M. (1999) Some issues arising in the systematic analysis of focus group materials. In R. S. Barbour & J. Kitzinger (eds.), *Developing Focus Group Research: Politics, theory and practice* (pp. 144-155). London: Sage.

Freidson, E. (1988) *Profession of Medicine: A study of the sociology of applied knowledge* (2nd ed.). Chicago: University of Chicago Press.

Freire, P. (1972) *Pedagogy of the Oppressed.* London: Penguin Books.

French, S. & Swain, J. (1997) Changing disability research: participatory and emancipatory research with disabled people. *Physiotherapy.* 83(1), 26-31.

Frese, F. J. & Davis, W. W. (1997) The consumer-survivor movement, recovery, and consumer professionals. *Professional Psychology: Research and practice.* 28(3), 243-245.

Gaster, L. (1996) Decentralisation, empowerment and citizenship. *Local Government Policy Making.* 22(4), 57-64.

Gaventa, J. & Cornwall, A. (2001) Power and knowledge. In P. Reason & H. Bradbury (eds.), *Handbook of Action Research: Participative inquiry and practice* (pp. 70-80). London: Sage.

Gelder, M., Gath, D. & Mayou, R. (1983) *Oxford Textbook of Psychiatry.* Oxford: Oxford University Press.

George, A. (1996) Methodological issues in the ethnographic study of sexuality: experiences from Bombay. In K. de Koning & M. Martin (eds.), *Participatory Research in Health: Issues and experiences* (pp. 119-129). London: Zed Books.

George, M. A., Green, L. W. & Daniel, M. (1996) Evolution and implications of P.A.R. for public health. *Promotion and Education.* 3(4), 6-10.

Gibson, C. H. (1991) A concept analysis of empowerment. *Journal of Advanced Nursing.* 16, 354-361.

Giddens, A. (1991) *Modernity and Self-Identity: Self and society in the late modern age*. Cambridge: Polity Press.

Gilliatt, S., Fenwick, J. & Alford, D. (2000) Public services and the consumer: empowerment or control? *Social Policy and Administration*. 34(3), 333-349.

Godin, P. (1996) The development of community psychiatric nursing: a professional project? *Journal of Advanced Nursing*. 23(5), 925-934.

Goffman, E. (1961) *Asylums: Essays on the social situation of mental patients and other inmates*. London: Penguin.

Goffman, E. (1990) *Stigma: Notes on the management of spoiled identity* (Penguin ed.). London: Penguin.

Gomm, R. (1993) Issues of power in health and welfare. In J. Walmsley, J. Reynolds, P. Shakespeare & R. Woolfe (eds.), *Health, Welfare and Practice: Reflecting on roles and relationships* (pp. 131-138). London: Sage.

Gomm, R. (1996) Reversing deviance. In T. Heller, J. Reynolds, R. Gomm, R. Muston & S. Pattison (eds.), *Mental Health Matters: A reader* (pp. 79-86). Basingstoke: Macmillan.

Goodley, D. (1997) Locating self-advocacy in models of disability: understanding disability in the support of self-advocates with learning difficulties. *Disability and Society*. 12(3), 367-379.

Goodwin, I., Holmes, G., Newnes, C. & Waltho, D. (1999) A qualitative analysis of the views of in-patient mental health service users. *Journal of Mental Health*. 8(1), 43-54.

Grace, V. M. (1991) The marketing of empowerment and the construction of the health consumer: a critique of health promotion. *International Journal of Health Services*. 21, 329-343.

Gradwell, L. (1993) Access, equal opportunities and anti-discriminatory legislation: the need for organisations of disabled people. In P. Beresford & T. Harding (eds.), *A Challenge to Change: Practical experiences of building user-led services*. London: National Institute for Social Work.

Graham, M. (2002) Creating spaces: exploring the role of cultural knowledge as a source of empowerment in models of social welfare in Black communities. *British Journal of Social Work*. 32, 35-49.

Grant, G. (1997) Consulting to involve or consulting to empower. In P. Ramcharan, G. Roberts, G. Grant & J. Borland (eds.), *Empowerment in Everyday Life: Learning disability* (pp. 121-143). London: Jessica Kingsley.

Green, L. W., O'Neill, M., Westphal, M. & Morisky, D. (1996) The challenges of participatory action research for health promotion. *Promotion and Education*. 3(4), 3-4.

Grierson, M. (2001) *Emerging Best Practice in Mental Health: User-based outcomes and recovery. Summary of the directional papers produced for the West Midlands Partnerships for Mental Health*. Manchester: Having a Voice.

Grimshaw, C. (1989) The poor laws revisited. In A. Brackx & C. Grimshaw (eds.), *Mental Health Care in Crisis* (pp. 125-138). London: Pluto Publishing.

Grove, B. (1998) Give them the money. *Mental Health Practice*. 2(1), 24-25.

Guba, E. G. & Lincoln, Y. S. (1988) Do inquiry paradigms imply inquiry methodologies? In D. M. Fetterman (ed.), *Qualitative Approaches to Evaluation in Education: The silent scientific revolution* (pp. 89-115). New York: Praeger.

Guba, E. G. & Lincoln, Y. S. (1989) *Fourth Generation Evaluation*. Newbury Park, CA: Sage.

Habermas, J. (1972) *Knowledge and Human Interests*. London: Heinemann.

Hall, B. L. (1978) Breaking the monopoly of knowledge: research methods, participation and development. In B. L. Hall & J. R. Kidd (eds.), *Adult Learning: A design for action* (pp. 155-168). Oxford: Pergamon Press.

Hall, B. L. (2001) I wish this were a poem of practices of participatory research. In P. Reason & H. Bradbury (eds.), *Handbook of Action Research: Participative inquiry and practice* (pp. 171-178). London: Sage.

Hallet, C. (1987) *Critical Issues in Participation*. Newcastle-upon-Tyne: Association of Community Workers.

Hammersley, M. (1995) *The Politics of Social Research*. London: Sage.

Hammersley, M. & Atkinson, P. (1995) *Ethnography: Principles in practice* (2nd ed.). London: Routledge.

Hannigan, B. (1999) Mental health care in the community: an analysis of contemporary public attitudes towards, and public representations of, mental illness. *Journal of Mental Health*. 8(5), 431-440.

Harris, R. (1997) Power. In M. Davies (ed.) *The Blackwell Companion to Social Work* (pp. 28-33). Oxford: Blackwell.

Harrison, J., MacGibbon, L. & Morton, M. (2001) Regimes of trustworthiness in qualitative research: the rigors of reciprocity. *Qualitative Inquiry*. 7(3), 323-345.

Harrison, S., Hunter, D. J., Marnoch, G. & Pollitt, C. (1992) *Just Managing: Power and culture in the National Health Service*. Basingstoke: Macmillan.

Hart, C., Jones, K. & Bains, M. (1997) Do the people want power? The social responsibilities of empowering communities. In P. Hoggett (ed.), *Contested Communities: Experiences, struggles, policies* (pp. 180-200). Bristol: The Policy Press.

Hart, E. & Bond, M. (1995) *Action Research for Health and Social Care: A guide to practice*. Buckingham: Open University Press.

Hart, N. (1985) *The Sociology of Health and Medicine*. Ormskirk: Causeway Press.

Hatfield, B. & Mohamad, H. (1994) Women, men and the Mental Health Act 1983. *Research Policy and Planning*. 12(3), 6-10.

Hayward, P. & Bright, J. A. (1997) Stigma and mental illness: A review and critique. *Journal of Mental Health*. 6(4), 345-354.

Heinz, L. C. & Grant, P. R. (2003) A process evaluation of a parenting group for parents with intellectual disabilities. *Evaluation and Program Planning*. 26, 263-274.

Henderson, D. J. (1995) Consciousness raising in participatory research: method and methodology for emancipatory nursing inquiry. *Advances in Nursing Science*. 17(3), 58-69.

Henderson, R. & Pochin, M. (2001) *A Right Result? Advocacy, justice and empowerment*. Bristol: The Policy Press.

Heron, J. (1981) Philosophical basis for a new paradigm. In P. Reason & J. Rowan (eds.), *Human Inquiry: A sourcebook of new paradigm research* (pp. 19-35). Chichester: John Wiley & Sons.

Heron, J. (1996) *Co-operative Inquiry: Research into the human condition*. London: Sage.

Herrenkohl, R. C., Judson, G. T. & Heffner, J. A. (1999) Defining and measuring employee empowerment. *Journal of Applied Behavioral Science*. 35(3), 373-389.

Higgins, J. W. (1999) Citizenship and empowerment: a remedy for citizen participation in health reform. *Community Development Journal*. 34(4), 287-307.

Hiroeh, U., Appleby, L., Mortensen, P. B. & Dunn, G. (2001) Death by homicide, suicide, and other unnatural causes in people with mental illness: a population-based study. *The Lancet*. 358, 2110-2112.

Hogg, C. (1999) *Patients, Power and Politics: From patients to citizens*. London: Sage.

Homan, R. (1991) *The Ethics of Social Research*. London: Longman.

Hopton, J. (1993) The contradictions of mental health nursing. *Nursing Standard.* 8(11), 37-39.

Howell, V. & Norman, I. (2000) Steering a steady course in an era of compulsory treatment: Taking mental health nursing into the millennium. *Journal of Mental Health.* 9(6), 605-616.

Hoy, D. C. (1986) Power, repression, progress: Foucault, Lukes, and the Frankfurt School. In D. C. Hoy (ed.), *Foucault: A critical reader* (pp. 123-147). Oxford: Basil Blackwell.

Hoyes, L., Jeffers, S., Lart, R., Means, R. & Taylor, M. (1993) *User empowerment and the reform of community care: a study of early implementation in four localities*. Bristol: School for Advanced Urban Studies.

Hudson, B. (1993) Michael Lipsky and street level bureaucracy. In M. Hill (ed.), *The Policy Process: A reader* (pp. 386-398). Hemel Hempstead: Harvester Wheatsheaf.

Hugman, R. (1991) *Power in Caring Professions*. Basingstoke: Macmillan.

Hugman, R. (1998) Social work and de-professionalization. In P. Abbott & L. Meerabeau (eds.), *The Sociology of the Professions* (2nd ed., pp. 178-198). London: UCL Press.

Humphries, B. (1994) Empowerment and social research: elements for an analytic framework. In B. Humphries & C. Truman (eds.), *Re-thinking Social Research: Anti-discriminatory approaches in research methodology*. Aldershot: Avebury.

Humphries, B. (1997) From critical thought to emancipatory action: contradictory research goals? *Sociological Research Online.* 2(1), http://www.socresonline.org.uk/socresonline/2-1/3.html.

Humphries, B., Mertens, D. M. & Truman, C. (2000) Arguments for an 'emancipatory' research paradigm. In C. Truman, D. M. Mertens & B. Humphries (eds.), *Research and Inequality* (pp. 3-23). London: UCL Press.

Hunter, D. J. (1994) From tribalism to corporatism: the managerial challenge to medical dominance. In J. Gabe, D. Kelleher & G. Williams (eds.), *Challenging medicine* (pp. 1-22). London: Routledge.

Illich, I. (1977) Disabling professions. In I. Illich, I. K. Zola, J. McKnight, J. Caplan & H. Shaiken, *Disabling Professions* (pp. 11-39). London: Marion Boyars.

Inyama, C. (2001) The potential impact of the Human Rights Act 1998 on mental health services. *The Mental Health Review.* 6(3), 29-32.

Jack, R. (1995) Empowerment in community care. In R. Jack (ed.), *Empowerment in Community Care* (pp. 11-42). London: Chapman & Hall.

Jacobson, N. (2001) Experiencing recovery: a dimensional analysis of recovery narratives. *Psychiatric Rehabilitation Journal*. 24(3), 248-256.

Janesick, V. J. (1998) The dance of qualitative research design: metaphor, methodolatry, and meaning. In N. K. Denzin & Y. S. Lincoln (eds.), *Strategies of Qualitative Inquiry* (pp. 35-55). Thousand Oaks, CA: Sage.

Janesick, V. J. (1999) A journal about journal writing as a qualitative research technique: history, issues and reflections. *Qualitative Inquiry*. 5(4), 505-524.

Johnson, T. J. (1972) *Professions and Power*. London: Macmillan.

Johnstone, L. (2000) *Users and Abusers of Psychiatry: A critical look at psychiatric practice* (2nd ed.). London: Brunner-Routledge.

Jones, I., Kent, L., Paul, M. & Craddock, N. (2001) Clinical implications of psychiatric genetics in the new millennium - nightmare or nirvana? *Psychiatric Bulletin*. 25, 129-131.

Kabeer, N. (1999) Resources, agency, achievements: reflections on the measurement of women's empowerment. *Development and Change*. 30, 435-464.

Karl, M. (1995) *Women and Empowerment: Participation and decision making*. London: Zed Books.

Keating, F. (1997) *Developing an Integrated Approach to Oppression*. London: CCETSW.

Kelly, D. (1993) Secondary power source: high school students as participatory researchers. *American Sociologist*. 24(1), 8-26.

Kemmis, S. (2001) Exploring the relevance of critical theory for action research: Emancipatory action research in the footsteps of Jurgen Habermas. In P. Reason & H. Bradbury (eds.), *Handbook of Action Research: Participative inquiry and practice* (pp. 91-102). London: Sage.

Kemshall, H. & Littlechild, R. (2000) Research informing practice: some concluding remarks. In H. Kemshall & R. Littlechild (eds.), *User Involvement and Participation in Social Care: Research informing practice* (pp. 233-242). London: Jessica Kingsley.

Kennedy, M. G., Schepp, K. G. & O'Connor, F. W. (2000) Symptom self-management and relapse in schizophrenia. *Archives of Psychiatric Nursing*. 14(6), 266-275.

Kincheloe, J. L. & McLaren, P. (2000) Rethinking critical theory and qualitative research. In N. K. Denzin & Y. S. Lincoln (eds.), *Handbook of Qualitative Research* (2nd ed., pp. 279-313). Thousand Oaks, CA: Sage.

Kinderman, P. & Cooke, A. (eds.) (2000) *Recent Advances in Understanding Mental Illness and Psychotic Experiences*. Leicester: The British Psychological Society.

Kinsey, D. (1987) Foreword. In P. Maguire, *Doing Participatory Research: A feminist approach* (pp. viii-xi). Massachusetts: Center for International Education, University of Massachusetts at Amherst.

Kitzinger, J. & Barbour, R. S. (1999) Introduction: the challenge and promise of focus groups. In R. S. Barbour & J. Kitzinger (eds.), *Developing Focus Group Research: Politics, theory and practice* (pp. 1-20). London: Sage.

Knox, M., Mok, M. & Parmenter, T. R. (2000) Working with the experts: collaborative research with people with an intellectual disability. *Disability and Society*. 15(1), 49-61.

Kuhn, T. S. (1970) *The Structure of Scientific Revolutions* (2nd ed.). Chicago: University of Chicago Press.

Kumar, S. (2000) Client empowerment in psychiatry and the professional abuse of clients: where do we stand? *International Journal of Psychiatry in Medicine*. 30(1), 61-70.

Kuper, L. (1974) *Race, Class and Power: Ideology and revolutionary change in plural societies*. London: Duckworth.

Kutchins, H. & Kirk, S. A. (1997) *Making Us Crazy. DSM: The psychiatric bible and the creation of mental disorders*. New York: The Free Press.

Laing, R. D. (1967) *The Politics of Experience and The Bird of Paradise*. Harmondsworth: Penguin.

Langan, J. & Lindow, V. (2004) *Living with risk: Mental health service user involvement in risk assessment and management*. Bristol: The Policy Press.

Langley, A., Denis, J.-L. & Lamothe, L. (2003) Process research in healthcare: towards three-dimensional learning. *Policy & Politics*. 31(2), 195-206.

Lapsley, H., Nikora, L. W. & Black, R. (2002) *"Kia Mauri Tau!" Narratives of recovery from disabling mental health problems*. Wellington: Mental Health Commission.

Lather, P. (1992) Critical frames in educational research: feminist and post-structural perspectives. *Theory into Practice*. 31(2), 87-99.

Laverack, G. & Wallerstein, N. (2001) Measuring community empowerment: a fresh look at organizational domains. *Health Promotion International*. 16(2), 179-185.

Lawton-Smith, S. (2001) Poverty and mental health: the work of the FOCUS on Mental Health Consortium. *Mental Health Review*. 6(3), 17-20.

Layder, D. (1997) *Modern Social Theory: Key debates and new directions*. London: UCL Press.

Le Grand, D. & Kessler, E. (1996) Self-assessment for mental health. *Management Issues in Social Care*. 3(4), 1-2.

Leckie, D. & Pickersgill, D. (1999) *The 1998 Human Rights Act explained*. London: The Stationery Office.

Lee, J. A. B. (2001) *The Empowerment Approach to Social Work Practice: Building the beloved community* (2nd ed.). New York: Columbia University Press.

Leff, J., Trieman, N., Knapp, M. & Hallam, A. (2000) The TAPS Project: a report on 13 years of research, 1985-1998. *Psychiatric Bulletin*. 24, 165-168.

Lerum, K. (2001) Subjects of desire: academic armor, intimate ethnography, and the production of critical knowledge. *Qualitative Inquiry*. 7(4), 466-483.

Lewis, G., Bebbington, P., Brugha, T., Farrell, M., Gill, B., Jenkins, R. & Meltzer, H. (1998) Socioeconomic status, standard of living, and neurotic disorder. *The Lancet*. 352, 605-609.

Lincoln, Y. S. & Guba, E. G. (2000) Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (eds.), *Handbook of Qualitative Research* (2nd ed., pp. 163-188). Thousand Oaks, CA: Sage.

Lindow, V. (1995) Power and rights: the psychiatric system survivor movement. In R. Jack (ed.), *Empowerment in Community Care* (pp. 203-221). London: Chapman & Hall.

Lindow, V. (1999) Survivor controlled alternatives to psychiatric services. In C. Newnes, G. Holmes & C. Dunn (eds.), *This is Madness: A critical look at psychiatry and the future of mental health services* (pp. 211-226). Ross-on-Wye: PCCS Books.

Lindow, V. (2001) Survivor research. In C. Newnes, G. Holmes & C. Dunn (eds.), *This is Madness Too: Critical perspectives on mental health services* (pp. 135-146). Ross-on-Wye: PCCS Books.

Lindow, V. (2002) Being ethical, having influence. *Openmind*. 116, 18-19.

Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E. & Dohrenwend, B. P. (1989) A modified labeling theory approach to mental disorders: an empirical assessment. *American Sociological Review*. 54, 400.

Lipsky, M. (1980) *Street-Level Bureaucracy: Dilemmas of the individual in public services*. New York: Russell Sage Foundation.

Litva, A., Coast, J., Donovan, J., Eyles, J., Shepherd, M., Tacchi, J., Abelson, J. & Morgan, K. (2002) 'The public is too subjective': public involvement in different levels of health-care decision making. *Social Science and Medicine*. 54, 1825-1837.

Lloyd, M., Preston-Shoot, M., Temple, B. & Wuu, R. (1996) Whose project is it anyway? Sharing and shaping the research and development agenda. *Disability and Society*. 11(3), 301-315.

Lukes, S. (1974) *Power: A radical view*. Basingstoke: Macmillan.

Lundin, R. K. (1998) Living with mental illness: a personal experience. *Cognitive and Behavioral Practice*. 5, 223-230.

Lupton, C. & Nixon, P. (1999) *Empowering Practice? A critical appraisal of the family group conference approach*. Bristol: The Policy Press.

Lupton, C., Peckham, S. & Taylor, P. (1998) *Managing Public Involvement in Healthcare Purchasing*. Buckingham: Open University Press.

Lupton, D. (1997) Foucault and the medicalisation critique. In A. Petersen & R. Bunton (eds.), *Foucault, Health and Medicine* (pp. 94-110). London: Routledge.

Macdonald, K. M. (1995) *The Sociology of the Professions*. London: Sage.

Macgregor-Morris, R., Ewbank, J. & Birmingham, L. (2001) Potential impact of the Human Rights Act on psychiatric practice: the best of British values? *British Medical Journal*. 322, 848-850.

Madriz, E. (2000) Focus groups in feminist research. In N. K. Denzin & Y. S. Lincoln (eds.) *Handbook of Qualitative Research* (2nd ed., pp. 835-850). Thousand Oaks, CA: Sage.

Maguire, P. (1987) *Doing Participatory Research: A feminist approach*. Massachusetts: Center for International Education, University of Massachusetts at Amherst.

Maguire, P. (1996) Proposing a more feminist participatory research: knowing and being embraced openly. In K. de Koning & M. Martin (eds.), *Participatory Research in Health: Issues and experiences* (pp. 27-39). London: Zed Books.

Maguire, P. (2001) Uneven ground: feminisms and action research. In P. Reason & H. Bradbury (eds.), *Handbook of Action Research: Participative inquiry and practice* (pp. 59-69). London: Sage.

Manning, N. (2000) Psychiatric diagnosis under conditions of uncertainty: personality disorder, science and professional legitimacy. *Sociology of Health and Illness*. 22(5), 621-639.

Manning, N., & Shaw, I. (1999) Mental health and social order. *Policy and Politics*. 27(1), 5-11.

Manning, S. S. (1998) Empowerment in mental health programs: listening to the voices. In L. M. Gutierrez, R. J. Parsons & E. O. Cox (eds.), *Empowerment in Social Work Practice: A sourcebook* (pp. 89-109). Pacific Grove: Brooks/Cole.

Marks, D. (1999) Dimensions of oppression: theorising the embodied subject. *Disability and Society*. 14(5), 611-626.

Martin, M. (1994) Developing a feminist participative research framework: evaluating the process. In B. Humphries & C. Truman (eds.), *Rethinking Social Research: Anti-discriminatory approaches in research methodology* (p. 123-145). Aldershot: Avebury.

Martin, M. (1996) Issues of power in the participatory research process. In K. de Koning & M. Martin (eds.), *Participatory Research in Health: Issues and experiences* (pp. 82-93). London: Zed Books.

Martin, M. (2000) Critical education for participatory research. In C. Truman, D. M. Mertens & B. Humphries (eds.), *Research and Inequality* (pp. 191-204). London: UCL Press.

Martyn, D. (2002) *The Experiences and Views of Self-Management of People with a Schizophrenia Diagnosis*. London: Rethink.

Marx, K. (1963) *Selected Writings in Sociology and Social Philosophy* (ed. T.B. Bottomore & M. Rubel). Harmondsworth: Penguin.

Marx, K. (1974) Theses on Feuerbach. In K. Marx & F. Engels, *The German Ideology Part One* (2nd ed., p. 121-123) (ed. C. J. Arthur). London: Lawrence & Wishart.

Mason, J. (2002) Qualitative interviewing: asking, listening and interpreting. In T. May (ed.), *Qualitative Research in Action* (pp. 225-241). London: Sage.

May, T. (1997) *Social Research: Issues, methods and process* (2nd ed.). Buckingham: Open University Press.

McDonald, S. (2001) Insider/outsider: roles and reflections on feminist participatory research. *Bridging the Gap: Feminisms and Participatory Action Research Conference*, 22nd-24th June, Boston.

McGowen, R. (1994) Power and humanity, or Foucault among the historians. In C. Jones & R. Porter (eds.), *Reassessing Foucault: Power, medicine and the body* (pp. 91-112). London: Routledge.

McLean, A. (1995) Empowerment and the psychiatric consumer/ex-patient movement in the United States: contradictions, crisis and change. *Social Science and Medicine*. 40(8), 1053-1071.

Mead, S. & Copeland, M. E. (2000) What recovery means to us: consumers' perspectives. *Community Mental Health Journal*. 36(3), 315-328.

Means, R. & Smith, R. (1998) *Community Care: Policy and practice* (2nd ed.). Basingstoke: Macmillan.

Means, R., Richards, S. & Smith, R. (2003) *Community Care: Policy and practice* (3rd ed.). Basingstoke: Palgrave Macmillan.

Melzer, D., Fryers, T. & Jenkins, R. (2002) *Inequalities and the Common Mental Disorders* (Executive Summary). Cambridge: Department of Public Health and Primary Care, Institute of Public Health.

Mental Health Foundation (1997) *Knowing Our Own Minds: A survey of how people in emotional distress take control of their lives*. London: Mental Health Foundation.

Merquior, J. G. (1991) *Foucault* (2nd ed.). London: Fontana Press.

Meulenberg-Buskens, I. (1996) Critical awareness in participatory research: an approach towards teaching and learning. In K. de Koning & M. Martin (eds.), *Participatory Research in Health: Issues and experiences* (pp. 40-49). London: Zed Books.

Mies, M. (1993) Towards a methodology for feminist research. In M. Hammersley (ed.), *Social Research: Philosophy, politics and practice* (p. 64-82). London: Sage.

Miles, M. B. & Huberman, A. M. (1994) *Qualitative Data Analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.

Milroy, A. & Hennelly, R. (1989) Changing our professional ways. In A. Brackx & C. Grimshaw (eds.), *Mental Health Care in Crisis* (pp. 175-189). London: Pluto Publishing.

Mind (1992) *The Mind Guide to Advocacy in Mental Health: Empowerment in action*. London: Mind.

Mind (2001a) *Report Highlights "Appalling" Drug Prescribing, Worse for Patients From Black and Minority Ethnic Communities*. Press Release, Tuesday 25th September.

Mind (2001b) *Mind Welcomes Confirmation That the Human Rights Act Applies to Psychiatric Patients Who Are Forcibly Treated*. Press Release, Tuesday 23rd October.

Mind (2002a) *Sexual Harassment on Mixed-Sex Wards Still a Major Problems Despite New Government Targets, Finds New Mind Survey*. Press Release, Wednesday 24th April.

Mind (2002b) *Mind Welcomes Ruling That Long Delays to Tribunal Hearings Breach Human Rights of Detained Patients*. Press Release, Tuesday 23rd April .

Moore, M., Beazley, S. & Maelzer, J. (1998) *Researching Disability Issues*. Buckingham: Open University Press.

Morgan, S. (1993) *Community Mental Health: Practical approaches to long-term problems*. London: Chapman & Hall.

Morrall, P. (1998) *Mental Health Nursing and Social Control*. London: Whurr Publishers.

Morris, B. & Faulkner, A. (2002) Doing it. *Openmind*. 116, 20.

Morris, J. (1991) *Pride Against Prejudice: Transforming attitudes to disability*. London: Women's Press.

Morris, J. (1997) Care or empowerment? A disability rights perspective. *Social Policy and Administration*. 31(1), 54-60.

Morrissey, J. (2000) Indicators of citizen participation: lessons from learning teams in rural EZ/EC communities. *Community Development Journal*. 35(1), 59-74.

Muijen, M. (1996) Scare in the community: Britain in moral panic. In T. Heller, J. Reynolds, R. Gomm, R. Muston & S. Pattison (eds.), *Mental Health Matters: A reader* (pp. 143-155). Basingstoke: Macmillan.

Mullaly, B. (1997) *Structural Social Work: Ideology, theory, and practice* (2nd ed.). Ontario: Oxford University Press.

Mullender, A. & Ward, D. (1991) *Self-Directed Groupwork: Users take action for empowerment*. London: Whiting & Birch.

Murray, R. (2002) *How to Write a Thesis*. Maidenhead: Open University Press.

Nash, F. (1993) Church-based organizing as participatory research: the Northwest Community Organization and the Pilsen Resurrection Project. *American Sociologist*. 24(1), 38-55.

National Institute for Mental Health in England (2003) *Inside Outside: Improving mental health services for Black and minority ethnic communities in England*. London: The Stationery Office.

National Institute for Mental Health in England (2004) *From Here to Equality: A strategic plan to tackle stigma and discrimination on mental health grounds, 2004-2009*. Leeds: NIMHE.

Neath, J. & Schriner, K. (1998) Power to people with disabilities: empowerment issues in employment programming. *Disability and Society*. 13(2), 217-228.

Nelson, G., Lord, J. & Ochocka, J. (2001) Empowerment and mental health in community: narratives of psychiatric consumer/survivors. *Journal of Community and Applied Social Psychology*. 11, 125-142.

Nelson, G., Ochocka, J., Griffin, K. & Lord, J. (1998) "Nothing about me, without me": participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors. *American Journal of Community Psychology*. 26(6), 881-912.

Newbigging, K. (2001) Promoting social inclusion. *Mental Health Review*. 6(3), 5-12.

Nicholls, V. (2001) *Doing Research Ourselves: A report of the Strategies for Living Research Support Project.* London: Mental Health Foundation.

Northway, R. (1998) *Oppression in the Lives of People with Learning Difficulties: A participatory study.* Unpublished doctoral dissertation, University of Bristol.

Northway, R. (2000a) Ending participatory research? *Journal of Learning Disabilities.* 4(1), 27-36.

Northway, R. (2000b) Finding out together: lessons in participatory research for the learning disability nurse. *Mental Health Care.* 31(7), 229-232.

Office of the Deputy Prime Minister (2004) *Mental Health and Social Exclusion: Social Exclusion Unit report.* Wetherby: ODPM Publications.

O'Hagan, M. (1993) *Stopovers on my Way Home from Mars: A journey into the psychiatric survivor movement in the USA, Britain and the Netherlands* (UK ed.). London: Survivors Speak Out.

Olesen, V. L. (2000) Feminisms and qualitative research at and into the millennium. In N. K. Denzin & Y. S. Lincoln (eds.), *Handbook of Qualitative Research* (2nd ed., pp. 215-255). Thousand Oaks, CA: Sage.

Oliver, J., Huxley, P., Bridges, K. & Mohamad, H. (1996) *Quality of Life and Mental Health Services.* London: Routledge.

Oliver, M. (1986) Social policy and disability: some theoretical issues. *Disability, Handicap and Society.* 1(1), 5-17.

Oliver, M. (1992) Changing the social relations of research production? *Disability, Handicap and Society.* 7(2), 101-114.

Oliver, M. (1993) Re-defining disability: a challenge to research. In J. Swain, V. Finkelstein, S. French & M. Oliver (eds.), *Disabling Barriers - Enabling Environments.* London: Sage/Open University Press.

Oliver, M. (1996) *Understanding Disability: From theory to practice.* Basingstoke: Macmillan.

Oliver, M. (1997) Emancipatory research: realistic goal or impossible dream? In C. Barnes & G. Mercer (eds.), *Doing Disability Research* (pp. 15-31). Leeds: The Disability Press.

Onken, S. J., Dumont, J. M., Ridgway, P., Dornan, D. H. & Ralph, R. O. (2002) *Mental Health Recovery: What helps and what hinders? A national research project for the development of recovery facilitating system performance indicators.* Alexandria, VA.: National Technical Assistance Center for State Mental Health Planning.

Ovretveit, J. (1998) *Evaluating Health Interventions: An introduction to evaluation of health treatments, services, policies and organizational interventions.* Buckingham: Open University Press.

Packham, C. (2000) Community auditing: appropriate research methods for effective youth and community work intervention. In B. Humphries (ed.), *Research in Social Care and Social Welfare: Issues and debates for practice* (pp. 102-118). London: Jessica Kingsley.

Papineau, D. & Kiely, M. C. (1996) Participatory evaluation in a community organization: fostering stakeholder empowerment and utilization. *Evaluation and Program Planning*. 19(1), 79-93.

Park, P. (1992) The discovery of participatory research as a new scientific paradigm: personal and intellectual accounts. *The American Sociologist*. Winter, 29-42.

Park, P. (1993) What is participatory research? A theoretical and methodological perspective. In P. Park, M. Brydon-Miller, B. Hall & T. Jackson (eds.), *Voices of Change: Participatory research in the United States and Canada*. Connecticut: Bergin & Garvey.

Park, P. (2001) Knowledge and participatory research. In P. Reason & H. Bradbury (eds.), *Handbook of Action Research: Participative inquiry and practice* (pp. 81-90). London: Sage.

Parsloe, P. (1996) Introduction. In P. Parsloe (ed.), *Pathways to Empowerment* (p. xvii-xxii). Birmingham: Venture Press.

Parsons, R. J., Gutierrez, L. M. & Cox, E. O. (1998) A model for empowerment practice. In L. M. Gutierrez, R. J. Parsons & E. O. Cox (eds.), *Empowerment in Social Work Practice: a sourcebook* (pp. 3-23). Pacific Grove: Brooks/Cole.

Patel, N. & Fatimilehin, I. A. (1999) Racism and mental health. In C. Newnes, G. Holmes & C. Dunn (eds.), *This is Madness: A critical look at psychiatry and the future of mental health services* (pp. 51-73). Ross-on-Wye: PCCS Books.

Patton, M. Q. (1990) *Qualitative Evaluation and Research Methods* (2nd ed.). Newbury Park, CA: Sage.

Payne, M. (1979) *Power, Authority and Responsibility in Social Services: Social work in area teams*. London: Macmillan.

Payne, M. (1997) *Modern Social Work Theory* (2nd ed.). Basingstoke: Macmillan.

Payne, S. (1996) Psychiatric care in the community: does it fail young men? *Policy and Politics*. 24(2), 193-205.

Pease, B. (2002) Rethinking empowerment: a postmodern reappraisal for emancipatory practice. *British Journal of Social Work*. 32, 135-147.

Peck, E. & Barker, I. (1997) Users as partners in mental health - ten years of experience. *Journal of Interprofessional Care*. 11(3), 269-277.

Penfold, P. S., & Walker, G. A. (1983) *Women and the Psychiatric Paradox.* Montreal: Eden Press.

Penn, D. L. & Wykes, T. (2003) Stigma, discrimination and mental illness. *Journal of Mental Health*, 12(3), 203-208.

Perkins, R. & Rinaldi, M. (2002) Unemployment rates among patients with long-term mental health problems. *Psychiatric Bulletin*. 26, 295-298.

Petras, E. & Porpora, D. (1993) Participatory research: three models and an analysis. *American Sociologist*. 24(1), 107-126.

Philip, E. & Nelson, B. (2001) ABWA – A better way ahead. In J. Read (ed.), *Something Inside So Strong: Strategies for surviving mental distress* (pp. 67-71). London: Mental Health Foundation.

Philo, G., Secker, J., Platt, S., Henderson, L., McLaughlin, G. & Burnside, J. (1996) Media images of mental distress. In T. Heller, J. Reynolds, R. Gomm, R. Muston & S. Pattison (eds.), *Mental Health Matters: A reader* (pp. 163-170). Basingstoke: Macmillan.

Philpot, T. (1994) *Managing to Listen: A guide to user involvement for mental health service managers*. London: King's Fund Centre.

Pilgrim, D. (2002) The biopsychosocial model in Anglo-American psychiatry: past, present and future? *Journal of Mental Health*. 11(6), 585-594.

Pilgrim, D. & Rogers, A. (1993) *A Sociology of Mental Health and Illness*. Buckingham: Open University Press.

Pilgrim, D. & Rogers, A. (1994) Something old, something new...: sociology and the organisation of psychiatry. *Sociology*. 28(2), 521-538.

Pilgrim, D. & Rogers, A. (1996) Two notions of risk in mental health debates. In T. Heller, J. Reynolds, R. Gomm, R. Muston & S. Pattison (eds.), *Mental Health Matters: A reader* (pp. 181-185). Basingstoke: Macmillan.

Pilgrim, D. & Rogers, A. (2003) Mental disorder and violence: An empirical picture in context. *Journal of Mental Health*. 12(1), 7-18.

Pilgrim, D. & Waldron, L. (1998) User involvement in mental health service development: how far can it go? *Journal of Mental Health*. 7(1), 95-104.

Porter, S. (1996) Contra-Foucault: soldiers, nurses and power. *Sociology*. 30(1), 59-78.

Priestley, M. (1999) *Disability Politics and Community Care*. London: Jessica Kingsley.

Punch, M. (1998) Politics and ethics in qualitative research. In N. K. Denzin & Y. S. Lincoln (eds.) *The Landscape of Qualitative Research: Theories and issues* (pp. 156-184). Thousand Oaks, CA: Sage.

Ralph, R.O. (2000) *A Synthesis of a Sample of Recovery Literature 2000.* Alexandria, VA: National Technical Assistance Center for State Mental Health Planning & National Association for State Mental Health Program Directors.

Ramazanoglu, C. with Holland, J. (2002) *Feminist Methodology: Challenges and choices*. London: Sage.

Ramcharan, P. & Borland, J. (1997) Preface. In P. Ramcharan, G. Roberts, G. Grant & J. Borland (eds.), *Empowerment in Everyday Life: Learning disability* (p. xi). London: Jessica Kingsley.

Ramcharan, P. & Grant, G. (1994) Setting one agenda for empowering persons with a disadvantage within the research process. In M. Rioux & M. Bach (eds.), *Disability Is Not Measles: New research paradigms in disability*. Ontario: L'Institut Roeher.

Rappaport, J. (1987) Terms of empowerment/exemplars of prevention: toward a theory for community psychology. *American Journal of Community Psychology*. 15(2), 121-148.

Rappaport, J. (1994) Empowerment as a guide to doing research: diversity as a positive value. In E. J. Trickett, R. J. Watts & D. Birman (eds.), *Human Diversity: Perspectives on people in context* (pp. 359-382). San Francisco: Jossey-Bass.

Read, J. (2001a) A note from the Editor. In J. Read (ed.), *Something Inside So Strong: Strategies for surviving mental distress* (pp. 5-6). London: Mental Health Foundation.

Read, J. (2001b) (ed.) *Something Inside So Strong: Strategies for surviving mental distress*. London: Mental Health Foundation.

Read, J. & Baker, S. (1996) *Not Just Sticks and Stones: A survey of the stigma, taboo and discrimination experienced by people with mental health problems.* London: Mind.

Read, J. & Wallcraft, J. (1992) *Guidelines for Empowering Users of Mental Health Services*. London: Confederation of Health Service Employees/Mind.

Reading, P. (1994) *Community Care and the Voluntary Sector: The role of voluntary organisations in a changing world*. Birmingham: Venture Press.

Reason, P. (1988) Introduction. In P. Reason (ed.), *Human Inquiry in Action: Developments in new paradigm research* (pp. 1-17). London: Sage.

Reason, P. (1998) Three approaches to participative inquiry. In N. K. Denzin & Y. S. Lincoln (eds.), *Strategies of Qualitative Inquiry* (pp. 261-291). Thousand Oaks, CA: Sage.

Reason, P. & Bradbury, H. (2001a) Preface. In P. Reason & H. Bradbury (eds.), *Handbook of Action Research: Participative inquiry and practice* (p. xxiii-xxxi). London: Sage.

Reason, P. & Bradbury, H. (2001b) Introduction: inquiry and participation in search of a world worthy of human aspiration. In P. Reason & H. Bradbury (eds.), *Handbook of Action Research: Participative inquiry and practice* (pp. 1-14). London: Sage.

Reason, P. & Rowan, J. (1981a) Foreword. In P. Reason & J. Rowan (eds.), *Human Inquiry: A sourcebook of new paradigm research* (p. xi-xxiv). Chichester: John Wiley & Sons.

Reason, P. & Rowan, J. (1981b) Issues of validity in new paradigm research. In P. Reason & J. Rowan (eds.), *Human Inquiry: A sourcebook of new paradigm research* (pp. 239-250). Chichester: John Wiley & Sons.

Reason, P. & Rowan, J. (1981c) Afterword. In P. Reason & J. Rowan (eds.), *Human Inquiry: A sourcebook of new paradigm research* (pp. 485-492). Chichester: John Wiley & Sons.

Repper, J. (2000) Adjusting the focus of mental health nursing: incorporating service users' experiences of recovery. *Journal of Mental Health*. 9(6), 575-587.

Repper, J. & Brooker, C. (1996) Public attitudes towards mental health facilities in the community. *Health and Social Care in the Community*. 4(5), 290-299.

Repper, J., Sayce, L., Strong, S., Willmot, J. & Haines, M. (1997) *Tall Stories from the Back Yard: A survey of 'nimby' opposition to community mental health facilities, experienced by key service providers in England and Wales*. London: Mind.

Richardson, M. (1997) Addressing barriers: disabled rights and the implications for nursing of the social construct of disability. *Journal of Advanced Nursing*. 25, 1269-1275.

Ridgway, P. (2001) Restorying psychiatric disability: learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*. 24(4), 335-343.

Rifkin, S. B., Lewando-Hundt, G. & Draper, A. K. (2000) *Participatory Approaches in Health Promotion and Health Planning: A literature review*. London: Health Development Agency.

Rissel, C. (1994) Empowerment: the holy grail of health promotion? *Health Promotion International*. 9(1), 39-47.

Ristock, J. L. & Pennell, J. (1996) *Community Research as Empowerment: Feminist links, postmodern interruptions*. Toronto: Open University Press.

Ritchie, J. & Spencer, L. (1994) Qualitative data analysis for applied policy research. In A. Bryman & R. G. Burgess (eds.), *Analyzing Qualitative Data* (pp. 173-194). London: Routledge.

Rogers, A. & Pilgrim, D. (1989) Mental health and citizenship. *Critical Social Policy*. 9(26), 44-55.

Rogers, A. & Pilgrim, D. (1995) Experiencing psychiatry: an example of emancipatory research. In G. Wilson (ed.), *Community Care: Asking the users* (pp. 198-211). London: Chapman & Hall.

Rogers, A. & Pilgrim, D. (1996) *Mental Health Policy: A critical introduction*. Basingstoke: Macmillan.

Rogers, A. & Pilgrim, D. (2003) *Mental Health and Inequality*. Basingstoke: Palgrave Macmillan.

Rogers, A., Pilgrim, D. & Lacey, R. (1993) *Experiencing Psychiatry: Users' views of services*. Basingstoke: Macmillan.

Rogers, E. S., Chamberlin, J., Ellison, M. L. & Crean, T. (1997) A consumer-constructed scale to measure empowerment among users of mental health services. *Psychiatric Services*. 48(8), 1042-1047.

Rose, D. (2001a) Terms of engagement. *Openmind*. March/April, 16-17.

Rose, D. (2001b) *Users' Voices: The perspectives of mental health service users on community and hospital care*. London: Sainsbury Centre for Mental Health.

Rose, D. (2002) 'Sure thing' (Service User Research Enterprise at London's Institute of Psychiatry). *Openmind*. 116, 22-23.

Rose, D. (2003) Partnership, co-ordination of care and the place of user involvement. *Journal of Mental Health*. 12(1), 59-70.

Rose, D., Fleischmann, P. & Wykes, T. (2004) Consumers' views of electroconvulsive therapy: a qualitative analysis. *Journal of Mental Health*. 13(3), 285-293.

Rose, S. (2001) Moving on from old dichotomies: beyond nature-nurture towards a lifeline perspective. *British Journal of Psychiatry*. 178 (suppl. 40), s3-s7.

Rosenhan, D. L. (1996) On being sane in insane places. In T. Heller, J. Reynolds, R. Gomm, R. Muston & S. Pattison (eds.), *Mental Health Matters: A reader* (pp. 70-78). Basingstoke: Macmillan.

Rowan, J. (1981) A dialectical paradigm for research. In P. Reason & J. Rowan (eds.), *Human Inquiry: A sourcebook of new paradigm research* (pp. 93-112). Chichester: John Wiley & Sons.

Sainsbury Centre for Mental Health (1998) *Briefing 4: Acute Problems*. London: Sainsbury Centre for Mental Health.

Sainsbury Centre for Mental Health (1999) *The National Service Framework for Mental Health: An executive briefing*. London: Sainsbury Centre for Mental Health.

Sainsbury Centre for Mental Health (2000) *An Executive Briefing on the implications of the Human Rights Act 1998 for mental health services*. London: Sainsbury Centre for Mental Health.

Saks, M. (1983) Removing the blinkers? A critique of recent contributions to the sociology of professions. *Sociological Review*. 31(1), 1-21.

Salter, M. & Byrne, P. (2000) The stigma of mental illness: how you can use the media to reduce it. *Psychiatric Bulletin*. 24, 281-283.

Sample, P. L. (1996) Beginnings: participatory action research and adults with developmental disabilities. *Disability and Society*. 11(3), 317-332.

Samson, C. (1995) Madness and psychiatry. In B. S. Turner & C. Samson, *Medical Power and Social Knowledge* (2nd ed., pp. 55-83). London: Sage.

Sashidharan, S. P. (2001) Institutional racism in British psychiatry. *Psychiatric Bulletin*. 25, 244-247.

Sayce, L. (1998) Stigma, discrimination and social exclusion: what's in a word? *Journal of Mental Health*. 7(4), 331-343.

Sayce, L. (2000) *From Psychiatric Patient to Citizen: Overcoming discrimination and social exclusion*. Basingstoke: Macmillan.

Sayce, L. (2001a) Social inclusion and mental health. *Psychiatric Bulletin*. 25, 121-123.

Sayce, L. (2001b) Not just users of services, but contributors to society: the opportunities of the disability rights agenda. *Mental Health Review*. 6(3), 25-28.

Sayer, A. (1992) *Method in Social Science: A realist approach*. London: Routledge.

Sayer, J., Ritter, S. & Gournay, K. (2000) Beliefs about voices and their effects on coping strategies. *Journal of Advanced Nursing*. 31(5), 1199-1205.

Schafer, T. (1996) Empowering service users: the myth, the reality and the hope. *Journal of Psychiatric and Mental Health Nursing*. 3, 391-394.

Scheff, T. J. (1966) *Being Mentally Ill: A sociological theory*. New York: Aldine Publishing.

Scheff, T. J. (1996) Labelling mental illness. In T. Heller, J. Reynolds, R. Gomm, R. Muston & S. Pattison (eds.), *Mental Health Matters: A reader* (pp. 64-69). Basingstoke: Macmillan.

Schulz, A. J., Israel, B. A. & Lantz, P. (2003) Instrument for evaluating dimensions of group dynamics within community-based participatory research partnerships. *Evaluation and Program Planning*. 26, 249-262.

Scull, A. T. (1979) *Museums of Madness: The social origins of insanity in nineteenth-century England.* London: Allen Lane.

Secker, J., Grove, B. & Seebohm, P. (2001) Challenging barriers to employment, training and education for mental health service users: the service user's perspective. *Journal of Mental Health.* 10(4), 395-404.

Segal, S. P., Silverman, C. & Temkin, T. (1995) Measuring empowerment in client-run self-help agencies. *Community Mental Health Journal.* 31(3), 215-227.

Shakespeare, T. & Watson, N. (1997) Defending the social model. *Disability and Society.* 12(2), 293-300.

Shaw, I. (1999) Evaluating quality in mental health services: contexts and issues. *Policy and Politics.* 27(1), 113-120.

Shaw, I. (2000) Just inquiry? Research and evaluation for service users. In H. Kemshall & R. Littlechild (eds.), *User Involvement and Participation in Social Care: Research informing practice* (pp. 29-44). London: Jessica Kingsley.

Sheldon, B. (1984) A critical appraisal of the medical model in psychiatry. In M. R. Olsen (ed.), *Social Work and Mental Health: A guide for the Approved Social Worker* (pp. 84-100). London: Tavistock Publications.

Sieff, E. M. (2003) Media frames of mental illnesses: The potential impact of negative frames. *Journal of Mental Health.* 12(3), 259-269.

Simon, B. L. (1990) Rethinking empowerment. *Journal of Progressive Human Services.* 1(1), 27-39.

Sines, D. (1994) The arrogance of power: a reflection on contemporary mental health nursing practice. *Journal of Advanced Nursing.* 20, 894-903.

Smale, G., Tuson, G., Biehal, N. & Marsh, P. (1993) *Empowerment, Assessment, Care Management and the Skilled Worker.* London: HMSO.

Sohng, S. S. L. (1998) Research as an empowerment strategy. In L. Gutierrez, R. Parsons & E. Cox (eds.), *Empowerment in Social Work Practice: A sourcebook* (pp. 187-203). Pacific Grove: Brooks/Cole.

Stainton, T. (1998) Intellectual disability, oppression and difference. In B. Lesnik (ed.), *Countering Discrimination in Social Work* (pp. 111-131). Aldershot: Ashgate.

Stanley, L. & Wise, S. (1983) *Breaking Out: Feminist consciousness and feminist research.* London: Routledge and Kegan Paul.

Stanley, L. & Wise, S. (1990) Method, methodology and epistemology in feminist research processes. In L. Stanley (ed.), *Feminist Praxis: Research, theory and epistemology in feminist sociology* (p. 20-60). London: Routledge.

Staples, L. H. (1990) Powerful ideas about empowerment. *Administration in Social Work*. 14(2), 29-42.

Stevenson, O. & Parsloe, P. (1993) *Community Care and Empowerment*. York: Joseph Rowntree Foundation.

Stoecker, R. & Bonacich, E. (1992) Why participatory research? *American Sociologist*. 23(4), 5-14.

Stone, E. & Priestley, M. (1996) Parasites, pawns and partners: disability research and the role of non-disabled researchers. *British Journal of Sociology*. 47(4), 699-716.

Survivors Speak Out (1988) *Self-Advocacy Action Pack: Empowering mental health service users*. London: Survivors Speak Out.

Swantz, M-L. & Vainio-Mattila, A. (1988) Participatory inquiry as an instrument of grass-roots development. In P. Reason (ed.), *Human Inquiry in Action: Developments in new paradigm research* (pp. 127-143). London: Sage.

Symonds, B. (1998) The philosophical and sociological context of mental health care legislation. *Journal of Advanced Nursing*. 27(5), 946-954.

Szasz, T. S. (1973) *Ideology and Insanity: Essays on the psychiatric dehumanization of man*. London: Calder & Boyars.

Tandon, R. (1996) The historical roots and contemporary tendencies in participatory research: implications for health care. In K. de Koning & M. Martin (eds.), *Participatory Research in Health: Issues and experiences*. London: Zed Books.

Taylor, M., Hoyes, L., Lart, R. & Means, R. (1992) *User Empowerment in Community Care: Unravelling the issues*. Bristol: School for Advanced Urban Studies.

Tetley, J. & Hanson, E. (2000) Participatory research. *Nurse Researcher*. 8(1), 69-88.

Thesen, J. (2001) Being a psychiatric patient in the community - reclassified as the stigmatized "other". *Scandinavian Journal of Public Health*. 29(4), 248-255.

Thomas, M. & Pierson, J. (1995) *Dictionary of Social Work*. London: Collins Educational.

Thompson, N. (1993) *Anti-Discriminatory Practice*. Basingstoke: Macmillan.

Thompson, N. (1998) *Promoting Equality: Challenging discrimination and oppression in the human services*. Basingstoke, Macmillan.

Thompson, N. (2001) *Anti-Discriminatory Practice* (3rd ed.). Basingstoke: Palgrave.

Thornicroft, G., Rose, D., Huxley, P., Dale, G. & Wykes, T. (2002) What are the research priorities of mental health service users? *Journal of Mental Health.* 11(1), 1-5.

Tolley, E. E. & Bentley, M. E. (1996) Training issues for the use of participatory research methods in health. In K. de Koning & M. Martin (eds.), *Participatory Research in Health: Issues and experiences* (pp. 50-61). London: Zed Books.

Townend, M. & Braithwaite, T. (2002) Mental health research - the value of user involvement. *Journal of Mental Health.* 11(2), 117-119.

Truman, C. (2000) New social movements and social research. In C. Truman, D. M. Mertens & B. Humphries (eds.), *Research and Inequality* (pp. 24-36). London: UCL Press.

Turner, B. S. (1987) *Medical Power and Social Knowledge.* London: Sage.

Turner, D. (2001) *Recovery in NSF: 'Wild geese'.* London: National Schizophrenia Fellowship.

Ulichny, P. (1997) When critical ethnography and action collide. *Qualitative Inquiry.* 3(2), 139-168.

Ungerson, C. (1997) Give them the money: is cash a route to empowerment? *Social Policy and Administration.* 31(1), 45-53.

Ussher, J. (1991) *Women's Madness: Misogyny or mental illness?* Hemel Hempstead: Harvester Wheatsheaf.

Wahl, O. F. (2003) Depictions of mental illness in children's media. *Journal of Mental Health.* 12(3), 249-258.

Walby, S., Greenwell, J., Mackay, L. & Soothill, K. (1994) *Medicine and Nursing: Professions in a changing health service.* London: Sage.

Wallcraft, J. (1994) Empowering empowerment: professionals and self-advocacy projects. *Mental Health Nursing.* 14(2), 6-9.

Wallcraft, J. (1998) Survivor-led research in human services: challenging the dominant medical paradigm. In S. Baldwin (ed.), *Needs Assessment and Community Care: Clinical practice and policy making* (pp. 186-208). Oxford: Butterworth-Heinemann.

Wallerstein, N. (1999) Power between evaluator and community: research relationships within New Mexico's healthier communities. *Social Science and Medicine.* 49, 39-53.

Walmsley, J. (2001) Normalisation, emancipatory research and inclusive research in learning disability. *Disability and Society.* 16(2), 187-205.

Ward, D. (2000) Totem not token: groupwork as a vehicle for user participation. In H. Kemshall & R. Littlechild (eds.), *User Involvement and Participation in Social Care: Research informing practice* (pp. 45-64). London: Jessica Kingsley.

Ward, D. & Mullender, A. (1993) Empowerment and oppression: an indissoluble pairing for contemporary social work. In J. Walmsley, J. Reynolds, P. Shakespeare & R. Woolfe (eds.), *Health, Welfare and Practice: Reflecting on roles and relationships* (pp. 147-154). London: Sage.

Warren, L. & Maltby, T. (2000) Averil Osborn and participatory research: Involving older people in change. In A. M. Warnes, L Warren & M. Nolan (eds.), *Care Services in Later Life: Transformations and critiques* (pp. 291-310). London: Jessica Kingsley.

Watt, S., Higgins, C. & Kendrick, A. (2000) Community participation in the development of services: a move towards community empowerment. *Community Development Journal*. 35(2), 120-132.

Waugh, P. (1999) Psychiatric patients will soon be able to vote. *The Independent*. 20th October, 1.

Whyte, W. F. (1991) *Participatory Action Research*. Newbury Park, CA: Sage.

Wilding, P. (1982) *Professional Power and Social Welfare*. London: Routledge and Kegan Paul.

Wilkinson, G. (1999) Theories of power. In G. Wilkinson & M. Miers (eds.), *Power and Nursing Practice* (pp. 7-23). Basingstoke: Macmillan.

Williams, J. (1999) Social inequalities and mental health. In C. Newnes, G. Holmes & C. Dunn (eds.), *This is Madness: A critical look at psychiatry and the future of mental health services* (pp. 29-50). Ross-on-Wye: PCCS Books.

Williams, M. & May, T. (2002) Commitment and investigation in knowing the social world. *International Journal of Social Research Methodology*. 5(1), 3-9.

Williamson, V. (1993) Users first: from policy to practice. In V. Williamson (ed.), *Users First: The real challenge for community care* (pp. 1-8). Brighton: University of Brighton.

Witz, A. (1994) The challenge of nursing. In J. Gabe, D. Kelleher & G. Williams (eds.), *Challenging Medicine* (pp. 23-45). London: Routledge.

Wolcott, H. F. (1990) *Writing up Qualitative Research*. Newbury Park, CA: Sage.

Wolff, G., Pathare, S., Craig, T. & Leff, J. (1996) Community knowledge of mental illness and reaction to mentally ill people. *British Journal of Psychiatry*. 168, 191-198.

Wolff, T. J. (1993) Coalition building: is this really empowerment? *American Public Health Association Annual Meeting*, 25th October, San Francisco.

Women in Mind (1986) *Finding our Own Solutions: Women's experience of mental health care*. London: Mind.

Wood, J. & Wilson-Barnett, J. (1999) The influence of user involvement on the learning of mental health nursing students. *Nursing Times Research*. 4(4), 257-270.

World Health Organisation (1992) *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical descriptions and diagnostic guidelines*. Geneva: WHO.

Wright, A. (1999) Exploring the development of user forums in an NHS trust. In M. Barnes & L. Warren (eds.), *Paths to Empowerment* (pp. 51-67). Bristol: The Policy Press.

Wykes, T. (2003) Blue skies in the Journal of Mental Health? Consumers in research. *Journal of Mental Health*. 12(1), 1-6.

Yeich, S. & Levine, R. (1992) Participatory research's contribution to a conceptualization of empowerment. *Journal of Applied Social Psychology*. 22(24), 1894-1908.

Young, I. M. (1990) *Justice and the Politics of Difference*. Princeton, NJ: Princeton University Press.

Zarb, G. (1992) On the road to Damascus: first steps towards changing the relations of disability research production. *Disability, Handicap and Society*. 7(2), 125-138.

Zigmond, A. S. (2001) Reform of the Mental Health Act 1983: the Green Paper. *Psychiatric Bulletin*. 25, 126-128.

Zimmerman, M. A. & Rappaport, J. (1988) Citizen participation, perceived control, and psychological empowerment. *American Journal of Community Psychology*. 16(5), 725-750.

Appendix 1: Consent form for co-researchers

RESEARCH PROJECT WRITTEN CONSENT FORM

to take part in group discussions and to release group discussion information

I agree to take part in group discussions about issues I face as a person using mental health services and ways of working on these problems.

I will take part in the group discussions under the following conditions:

- I understand that I have the right to stop taking part in the group discussions at any time during the project, without having to explain why I have done this.

- I will let the discussions be tape recorded. I understand that the discussions are being taped so that nothing is missed and so that my words are not changed or misunderstood. I can turn off the tape recorder at any time during the discussions if I do not want something I say to be taped. I understand that the tape will only be listened to by Fen Starkey and will not be given to anyone else.

- I agree to let Fen Starkey use the information from the discussion in the report she writes for her doctoral study and in other articles or reports she publishes. However, I understand that my **anonymity** and **confidentiality** will be protected: she will not use my name or any other information that other people could recognise about me in anything she writes.

- I understand that as a group we will have the right to get a copy of notes from our discussions and to check them to make sure we are happy with them. If we aren't, we can suggest and agree changes to make them clearer or more accurate, or we can add new information.

Signature .....

Name (printed) .....

Date .....

Appendix 2: Plans for group sessions

Programme for Session 1, 12th May 1998

2.30 **Welcome and thank you - round of names**

2.40 **Brief input on project (with handout)**

2.50 **Name bingo** - purpose is to find out more about each other and have a bit of fun!

3pm **Coffee break**

3.30 **Ground rules** – the reason we need them is because we are going to be working together as a group, talking about ourselves and our experiences, and we need to feel like we can trust each other and feel safe in this group. Ground rules agreed by open group (have on flipchart?) - read through. Anything else that anyone wants to add?

3.40 **Exercise in pairs** - a few minutes each to say something about yourself - your family, your likes and dislikes. You need to listen and remember as much as you can, because we're then going to go round and introduce our partner to the group.

3.50 **Group round.** NB - Only share things about your partner that they are happy for you to tell everyone.

4pm **Next week** - going to do some more work, mostly in pairs and small groups, talking about ourselves and our experiences, and finding out more about others. Going to try and have some fun too! Thank you for coming.

Programme for Session 2, 19th May 1998

a) **Welcome and opening round** – "One thing I've enjoyed doing in the last week".
Ground rules – typed up and on wall.

b) **Research conditions** – input and consent forms.
As discussed last week, working with the group is for my studies at Bristol University for PhD.
Good practice for social researchers to make sure that the group they are working with have fully agreed to this. So there are certain things I need to agree with you to make sure you're happy working in a group with me in this way.

1. Need to use info. from our discussions in writing up my research report (thesis). But anonymity and confidentiality will be assured (explain e.g. no names).
2. To be able to work with you in this group and remember what you say, I'd like to tape record our group discussions. But I'll be the only person who has this tape – I won't give it or play it to anyone else. I'll type it up and then bring copies of these notes to each meeting. You can read through them and make sure you're happy with them. If you're not, we can change them – add/remove things.

To go ahead with the research, I need each of you to be happy with this and agree to it. **Any questions about what I've said so far?**
I have written consent forms for you to sign – I know this seems formal, but it's to protect you so that you know what your rights are working with this group and what I'm going to do with the information we learn in this group.
Give out paper and read through out loud. Any questions and anything not happy with? Get signatures.

c) **Problem-posing**
In these sessions, we're going to be thinking about problems you face as mental health service users, about what causes these problems, and about ways of solving these problems.
To start the process, we need to think about your own experiences. To do this, I would like you to think about the question **"What problems have you faced as a person using mental health services?" (write on flipchart).**
Think back to when you first started using mental health services.
NB. Check out with the group how they would be most comfortable starting this off – I realise they might not want to talk to the whole group about experiences at first. Want to work in 2/3/4s?

(If doesn't work, wordstorm – call out in any order, don't need to explain or justify, say anything no matter how big or small).

Ideal – small groups – split in two, facilitator in each (ask <u>each</u> person to speak).
Piece of paper for each group to note down key problems.

cont'd/...

.../cont'd

Purpose of doing this is to share experiences- so that you can support each other and so that we can find out things that you have in common.

d) **Whole group feedback (record?)** – not going to ask you to go into any detail if you don't want to.
What do you feel are the main problems you've experienced? (Anyone to start? If not, go round the group, or ask what did your group come up with?).

e) **Summing up**
Important themes here – will form the basis of our discussions in coming weeks.
Need to agree on format for meetings – could take a theme each week to look at more closely (name problems, identify causes, discuss possibilities for solution), plus leave some time for general open-ended discussion. **Any other suggestions for ways of structuring future meetings? Or are you happy with this?**

f) **Closing round** – "One thing I'm looking forward to this week".
Could be anything.

Programme for Session 3, 26th May 1998

1) Welcome

- Check who's present
- People not there last week – recap, consent forms (tape recording)
- Remind everyone of ground rules

2) Last week's discussion

- Question was "What problems have you faced as a person using mental health services?"
- Copy of full transcript of session – to read at break/after session?
- Main themes identified – copy of sheet for everyone:
  - Agreed that these are what we talked about last week?
  - Anything anyone wants to ADD under any of these themes?
  - Any OTHER themes?

(Other questions to ask if we move on:

- Any other problems you experience in day-to-day life that you think are because you are a mental health service user?
- Do you feel that people discriminate against you in any way because you are a mental health service user? Who does? How?

3) Summing up

- Future sessions – we need to agree on a format – could take a theme each week to look at more closely (name problem, identify causes, discuss possibilities for solution) and leave some time for general open-ended discussion. **Any other suggestions for ways of structuring sessions? Or happy with this?**

4) Closing activities

- Round of things I'm looking forward to/things I like about summer.
- Game?

Programme for Session 4, 2nd June 1998

1) Welcome

- Icebreaker – one nice thing that you've done this week.

2) Last week's discussion

- Copy of full transcript again – to read later/take away with you if you want to.

- Main themes identified – read through and see if there's anything you want to add to each point.

- Have we covered the things that worry you the most? **Q: What worries you the MOST?**

3a) What do you think are some of the *reasons* behind these problems?

3b) What would you like to change?

- Let's move on to think about what you would like to see change about services and the way you've been treated.

- Obviously, we won't necessarily be able to change these things, but good to think about what you would like to see – we might decide to put this information together so that people can see what <u>you</u> would like to see improve.

- **Q: What would make your life better/easier? What would you like to see change in these areas we've talked about?**
- (Prompt if necessary: hospital care, care at home, medication, GP services, day care, transport, things to do, housing)

4) Summing up

- I will type all this up and bring it along next week for you to look at if you want to.

- But there is a barbecue next week so the group won't be meeting.

- The following week, I've got to go to a meeting at work which I can't change – I will only be able to get here for the second half of the session i.e. 3.30 to 4pm.

- What would you like to do in the first half of the session? I could give Sue an activity to do with you. Or you could play a game? Or talk about something of your choice? It's up to you!

5) Closing round

- How are you feeling about these sessions so far?

Programme for Session 5, 16th June 1998 (3.30-4)

1) Review session

- What came up in the first half of the session – your feelings about how sessions have gone so far?

- What about the way you want the group to carry on? Any issues?

- Anything else on the sheet not covered?

2) Previous discussion

- Copy of full transcript again.

- Main themes picked out:
  a) Any other things that worry you?
  b) Reasons behind some of the problems we've talked about so far.

- Anything to add? (Amy?)

3) What would you like to change?

- Let's move on to think about what you would like to see change about services and the way you've been treated.

- Obviously, we won't necessarily be able to change these things, but it's good to think about what you would like to see – we might decide to put this information together so that people can see what you would like to see improve.

- **Q: What would make your life better/easier? What would you like to see change in these areas we've talked about?**
- (Prompt if necessary: hospital care, care at home, medication, GP services, day care, transport, things to do, housing).

4) Closing round

- Something you're looking forward to this week.

(NB. Not done as only one co-researcher present, so only point 1 covered).

Programme for Session 6, 23rd June 1998

1) Last full session of group

- Copy of full transcript again.

- Main themes picked out:
  a) Any other things that worry you?
  b) Reasons behind some of the problems we've talked about so far.

- Anything to add? (Amy?)

2) Review session

- Thank you for input – main themes noted by Sue – OK? Anything to add?

- Copy of the transcript from discussion with Mike for info.

- Only point to check with other co-researchers – issue of other people wanting to join. Keep it a closed group?

3) What would you like to change?

- Let's move on to think about what you would like to see change about services and the way you've been treated.

- Obviously, we won't necessarily be able to change these things, but it's good to think about what you would like to see – we might decide to put this information together so that people can see what you would like to see improve.

- **Q: What would make your life better/easier? What would you like to see change in these areas we've talked about?**
- (Prompt if necessary: hospital care, care at home, medication, GP services, day care, transport, things to do, housing)

4) What could we do about some of the issues you've raised?

- **Wordstorm** to think of all the possible things we could do and people we could talk to.
- (This is the 'research' part of the project – finding out more information about issues raised. What do we mean by 'research'?).

5) Closing round

- Something you're looking forward to this week.

Programme for Session 7, 30th June 1998

1) Last session

- Copy of full transcript for info.

- Main things we talked about:
  - ➢ How to move on to get answers to why these problems exist.
  - ➢ (You might decide that just having this information is enough, to answer some of <u>your</u> questions, or might want to <u>use</u> this information and the information we've produced in this group through talking to take more action – produce a report/leaflet, hold meetings, discuss with other people using this service or with host organisation workers).
  - ➢ We started to think about possible group activities e.g. writing to GPs, inviting people here to talk to them and ask questions.
  - ➢ We started to think about the sorts of people you might want to invite, and the sorts of questions you might want to ask.

Rest of programme to include (in appropriate order):

a) Doing 'research'

- This phase of the project is the 'research' phase.
- What do we mean by 'research'? (Group understanding?).
- Ways of doing research, i.e. finding out information, include interviewing people, on their own or in a group; sending people questionnaires so that they can fill in their views; looking at existing information e.g. statistics, government reports and policy documents, medical information, to find out answers to your questions; observing things that go on; sending people a tape and a list of questions for them to record their answers to those questions.
- It's up to you to decide what you feel most comfortable with and what you think will give you answers to your questions.

b) Wordstorm ideas to add to already suggested activities

- i.e. inviting people to attend, and writing to GPs.
- If there are no other suggestions, we need to AGREE on the first action to be taken.

c) First group activity to be done – need to decide

- what information you want to ask them – what information would you want to get? (list of questions)
- how would you want it to be structured/carried out (e.g. if it's an interview – how many people to invite at a time? Who would run the interview? How would the interview run?)

(If we get stuck on these, go back to thinking about how the group would like after-care services to improve/what they would like to see change about services and the way they've been treated).

Programme for Session 8, 7th July 1998

1) Last session

- Copy of full transcript for info.

- Main things we talked about:

  - Things the group could do next e.g. writing to GPs, sending out a survey, inviting people here to talk to them and ask questions.
  - We started to think about the sorts of questions you might want to ask – **these are the questions you've come up with over the last two weeks (read through).**

2) Questions to ask

- Any other questions you can think of in advance that you would want to ask professionals (either in an interview or questionnaire survey)?

- (Prompt: we've talked about loneliness and isolation; day care services being closed; lack of understanding from GPs; bad experiences at hospital; lack of support after discharge; care plan reviews not happening; worries about relying on family members to do everything at home; transport; housing; need for support at home; being dropped by workers; the effects of depression).

3) Way forward

- Sue and I will come up with possible people to invite – we will try and contact people this week and let you know what they say. It might take longer than one week. We might be able to only get one person at a time – we could do a 'trial run' with one person and see how it goes/see how you feel about it.

4) What would you like to change?

- Something that we might need to think about is **what you would like to see change** about services and the way you've been treated – professionals coming here might ask you this, and it would be good to have thought about the answers.

- **Q: What would make your life better/easier? What would you like to see change in these areas we've talked about?**
- (Prompt: we've talked about loneliness and isolation; day care services being closed; lack of understanding from GPs; bad experiences at hospital; lack of support after discharge; care plan reviews not happening; worries about relying on family members to do everything at home; transport; housing; need for support at home; being dropped by workers; the effects of depression).

5) Closing round

- One thing you're looking forward to this week.

Programme for Session 9, 14th July 1998

1) Last session

- Copy of full transcript for info.

2) Interviews with professionals

- Arrangements for interviews with mental health professionals – read through theme sheet, and check out each point with all co-researchers.

3) Letter

- I agreed to draft a letter to send to mental health professionals inviting them to come.
- Read through copy of letter – everyone agreed? Any changes – things to add/take out?

4) The summer

- Many thanks to all for being involved in the project so far – I hope that you have found it useful/worthwhile, and that you'll still be involved when we come back together again in September.
- **What are you looking forward to over the summer?**

5) Game

- Ask the group what game they'd like to play (if no suggestions – charades, who am I?)

Programme for Session 10, 22nd September 1998

1) **Opening round**

- Introduction – nice things you've done over the summer.

2) **Interviews update**

- I've sent out letters to CPN, consultant at hospital, three social services team managers, GP, two people at Health Authority and councillor (Chair of Social Services Committee).

- I was contacted (without me chasing!) by CPN and social services community care team leader – both said they would be interested in being involved.

- So I have set up an interview with them both on 20th October.

- The councillor wrote back – he's happy to do the interview, which I'm very pleased about. I have also been trying to get hold of someone at the Health Authority to come along to that interview with the councillor – head of mental health team which makes decisions about what health services to buy in this area. But I have phoned twice and sent an urgent fax and no response. **Do you want me to keep chasing him, or are you happy to have the councillor here on his own?**

- The councillor is coming on 27th October – one week after our first interview.

- I haven't chased the other people I wrote to yet, as you said you only wanted two interviews to start with, but if they go well and you want more, we can contact them again.

- A trip is organised on 13th October, so we have **three sessions**, including today, to prepare.

3) **Questions**

- The community care team leader did want a clearer idea of what sort of questions we might be asking, so I said I could send her a list of the sorts of things – are you happy with this?

- (If yes) That's what we need to do today – come up with a list you're happy to send out to people coming.

- Use the previous list as prompt – focus on **jobs** of people coming, and appropriate questions to ask them. Think about their roles/areas of work.

4) **Practicalities (or next week)**

- We need to think about how we're going to run interviews – timing, how to put questions, ground rules.

Programme for Session 11, 29th September 1998

1) **Interviews update**

- I still haven't heard from Health Authority, but I haven't had time to chase.
- I will do that next week, plus will try to organise a GP interview.

2) **Update on presenting to other centre users**

- What was discussed at the centre users' meeting today?
- How do you want to present it to them? Update on everything so far, or just talk about interviews coming up? Who do you want to lead this?

3) **Questions**

- Main aim today – to finalise a list of questions.
- Any you've thought up and brought along?
- Anything else to add to this list?
- Are you happy for me to send this list to people coming?

4) **Practicalities**

- We need to think about how we're going to run these interviews:
- Who is going to chair them?
- What time shall we have them? 2-3? 2.30-3.30? We could have some time afterwards to talk about what they've said.
- How are we going to ask questions? Are we going to take it in turns? Is one person going to be spokesperson?
- Are you happy for me to tape the interviews?

5) **Closing round**

- One nice thing you're looking forward to this week.

(NB. Point 2 did not happen as co-researchers did not present the project at the centre users' meeting).

Programme for Session 12, 6th October 1998

1) Interviews update

- I have now got hold of the man from the Health Authority – he's happy to come along to the interview with the councillor.
- I have tried to contact the GP – no luck yet – will keep trying this week.

2) Feedback from centre users' meeting

- Anything they wanted to add to list?
- What about inviting any of them along to meetings?

3) List of questions (handout)

- Anything else at all to add?
- Emphasise that we don't have to stick to this – just a guide, for our benefit.
- NB. The people coming want some idea of topics to be covered – is it OK for me to send them this list?

4) Practicalities (handout)

- This is the last session before our first visitors come, so we need to agree:

- The timing of interviews – last week, you suggested 2 to 3, with a break from 3 to 3.30, and then 3.30 to 4 to reflect on what came up.

- Who is going to chair the interview i.e. introduce people, make sure that it runs to time, make sure everyone gets the chance to ask questions, etc.?

- Asking the questions – Is everyone happy to ask questions? It will be important that we make the best use of time, and so we need to be prepared to speak up.

- Recording the interviews – is it OK for me to tape record and then type up?
- If we do this, we will need to try and remember to speak one at a time, so that we can hear what people are saying.

- Refreshments – I'll make sure there is tea, coffee and biscuits over here.

5) Confirm dates

- 20th October – CPN and Community Care Team Leader
- 27th October – Chair of Social Services and Health Authority representative

- It's really important that you come to these interviews if you can.
- If any problems are likely with transport, please let us know beforehand and we will try and sort something out.

6) Closing round

- How are you feeling about these people coming along?

Programme for Session 13, 20th October 1998

1) **Welcome**
2) **Round of introductions**

3) **Introduction (background to our work)**

- The group consists of people who **expressed interest** in the project - part of my **PhD.**
- We've been working together since **April,** meeting most weeks.
- Have spent considerable time exploring group members' **experiences of and views on** mental health services.
- We then identified **areas we wanted to find out more about** - questions we wanted to ask people working in mental health.
- We decided that we wanted to **ask these questions face-to-face** – we invited you here – you kindly agreed to come to answer the group's questions.

4) **Ground rules**

- It's important to stress that the **two visitors don't work in this area** – we didn't want people you might be working with.
- So they **will know about services** and related issues, **but not necessarily specific services in this area.**

- Before we start, **CONFIDENTIALITY** is an important issue to clarify.
- The information collected today may be **used by myself,** in my PhD thesis, **and by the group** – they may want to feed back to other centre users, or to write something for a newsletter or other publication they choose.
- But it's agreed that **your names won't be used** – it will be presented anonymously, as 'a CPN' and 'a community care team leader'.
- I would like to **tape** today, to make sure we catch everything – but the tape will **only be heard by me, and the transcript will be confidential** to the people here.
- Similarly, **service users here want their confidentiality to be respected** – they want to ensure that their **names aren't used** in any reporting of this meeting, and that what they say won't in any way **affect their treatment** or access to services.

- **Anything else** anyone wants to clarify before we start?

5) **Questions**

- We've prepared a list of questions – **topics sent to visitors in advance.**
- We know that you **won't necessarily feel able to comment on all** the issues raised.
- It might be useful to start with **more details on what your jobs involve,** and then move on to questions.

6) **Closing**

- Thank you for coming, and for your time.
- It's been a very useful opportunity.

Programme for Session 14, 27th October 1998

1) **Welcome**
2) **Round of introductions**

3) **Introduction (background to our work)**

- The group consists of people who **expressed interest** in the project - part of my **PhD.**
- We've been working together since **April,** meeting most weeks.
- Have spent considerable time exploring group members' **experiences of and views on** mental health services.
- We then identified **areas we wanted to find out more about** - questions we wanted to ask people working in mental health.
- We decided that we wanted to **ask these questions face-to-face** – we invited you here – you kindly agreed to come to answer the group's questions.

4) **Ground rules**

- Before we start, **CONFIDENTIALITY** is an important issue to clarify.
- The information collected today may be **used by myself,** in my PhD thesis, **and by the group** – they may want to feed back to other centre users, or to write something for a newsletter or other publication they choose.
- But it's agreed that **your names won't be used** – it will be presented anonymously, as 'a health authority manager' and 'a local councillor'.
- I would like to **tape** today, to make sure we catch everything – but the tape will **only be heard by me, and the transcript will be confidential** to the people here.
- Similarly, **service users here want their confidentiality to be respected** – they want to ensure that their **names aren't used** in any reporting of this meeting, and that what they say won't in any way **affect their treatment** or access to services.

- **Anything else** anyone wants to clarify before we start?

5) **Questions**

- We've prepared a list of questions – **topics sent to visitors in advance.**
- We know that you **won't necessarily feel able to comment on all** the issues raised.
- It might be useful to start with **more details on what your jobs involve,** and then move on to questions.

6) **Closing**

- Thank you for coming, and for your time.
- It's been a very useful opportunity.

Programme for Session 15, 3rd November 1998

1) Feedback on interviews

- How do you think the interviews went?
- How are you feeling now?

2) Main themes

- NB. Note that I haven't been able to type up first interview yet, so I just have the main themes from last week.
- I have the full transcript of last week if you want to read it.

- What were the main points you remember/that came out for you?

(Then give out summary sheet)

- Go through main themes – what do you think of what they said?
- Any other comments on these themes?

3) Future plans

- I would like to write and thank people for coming, and send them the transcript – are you happy with that?

- Update on GP interviews (NB. OK to only have one? – money).

- Anyone else you'd like me to invite?

- Any thoughts yet on what you might want to do with this information?

4) Next week

- We'll have the chance to look at the information we've gathered and think about what you want to do with that.
- Or we'll have the GP interview, but it's not likely.

Programme for Session 16, 10th November 1998

1) Update on interviews

- I have written to thank interviewees.
- Update on taxis?
- I still haven't been able to get the **tape of the first interview** done, but I'm hoping to have it ready by the next time I see you.
- But I **have arranged a GP** interview, for **next week.**
- This is good – it **doesn't clash** with any of the other meetings.
- I can get **payment** for it from the University.

2) GP interview

- We need to **prepare** for this interview.
- We do have the questions we did before, but also we need to think about **specific questions** that you might want to ask GPs (e.g. medication, GP role in after-care and community care services, training in mental health).
- So I want to spend some time today just thinking about questions for the GP **(use sheet as prompt).**
- Practicalities – the interview will run from 2-3pm, break 3-3.30, then feedback 3.30-4 if you are still here.
- Again, it's very **important that everyone tries to come,** particularly as we're having to pay her!

3) Future sessions (give out sheet)

- After the GP interview, there are **three weeks** of other activities.
- Then we're back together **before Christmas** – to start looking at all the information, and to think about what we're going to do after Christmas.
- Christmas week – I'll be on **holiday** and you'll probably be doing other things here.
- We'll **start again on 5th January** – there is a range of things we might want to do.

Programme for Session 17, 17th November 1998

1) **Welcome**
2) **Round of introductions**

3) **Introduction (background to our work)**

- The group consists of people who **expressed interest** in the project - part of my **PhD.**
- We've been working together since **April,** meeting most weeks.
- Have spent considerable time exploring group members' **experiences of and views on** mental health services.
- We then identified **areas we wanted to find out more about** - questions we wanted to ask people working in mental health.
- We decided that we wanted to **ask these questions face-to-face** – we invited you here – you kindly agreed to come to answer the group's questions.

4) **Ground rules**

- Before we start, **CONFIDENTIALITY** is an important issue to clarify.
- The information collected today may be **used by myself,** in my PhD thesis, **and by the group** – they may want to feed back to other centre users, or to write something for a newsletter or other publication they choose.
- But it's agreed that **your names won't be used** – it will be presented anonymously, as 'a GP'.
- I would like to **tape** today, to make sure we catch everything – but the tape will **only be heard by me, and the transcript will be confidential** to the people here.
- Similarly, **service users here want their confidentiality to be respected** – they want to ensure that their **names aren't used** in any reporting of this meeting, and that what they say won't in any way **affect their treatment** or access to services.

- **Anything else** anyone wants to clarify before we start?

5) **Questions**

- We've prepared a list of questions – **topics sent to visitors in advance.**
- We know that you **won't necessarily feel able to comment on all** the issues raised.
- It might be useful to start with **more details on what your jobs involve,** and then move on to questions.

6) **Closing**

- Thank you for coming, and for your time.
- It's been a very useful opportunity.

Programme for Session 18, 15th December 1998

1) Taxis

- Show letter from the councillor, our letters sent, and the reply from the councillor – comments?
- Any other news on this?
- What shall we do now? Wait to hear from Director of Social Services?

2) Feedback from GP

- Give out notes of phone conversation.
- Any other comments?
- Permission for her to show an **anonymous** version of our discussion to someone else?

3) Progress so far

- What do you think/feel about what you as a group have achieved so far? And the work we have done?

4) What next?

- We need to think about what if anything you want to do after Christmas.

- Sessions could include:
- interviewing people from user forum/other people you want to invite along;
- analysing the information we've collected;
- deciding what to do with this information – do you want to take any more action?
- evaluating what we've done in the group – group discussion and individual meetings.

- This last point is important for me – even if you decide you don't want any more sessions, I do need to talk to you to find out how you feel about this process that we've been through together, for my studies.

5) Dates for next session(s)

- First meeting on 5th January? Times?

Programme for Session 19, 5th January 1999

1) **Welcome back and update on progress**

- Taxis - has everyone seen letters? Any other news? Any other action for now?
- Celia phoned to thank us for inviting her (has everyone seen the notes?)

2) **Progress so far**

- What the group has achieved so far (on A3 paper) - how do you feel about all this?
- What else do you feel we have achieved?

3) **What next?**

- We need to think about what if anything you want to do next - we could:
    - have more interviews e.g. people from user forum;
    - analyse the information we got from our interviewees - what are the most important points?
    - decide what to do with this information - do you want to take any more action?
    - evaluate what we've done in the group.

- (This last point is important for me - even if you decide you don't want any more meetings, I do need to talk to you to find out how you feel about this process that we've been through together, for my studies).

- We could come up with an action plan for things to do:
    - as individuals;
    - as a group;
    - with the rest of host organisation staff and members.

- You might decide that you want to keep this group going, or join in with the centre users' group and take up some of these issues via them.

4) **Main themes**

- It's a while since we had the interviews – I have done sheets with main points to refresh memories (hand out).

- What do **you** think were the most important or interesting points the interviewees made in answer to your questions?

- Are there any of these points that you want to do something about? (individually, as group, as host organisation).

5) **Dates for next sessions**

- Do you want to carry on having weekly sessions?
- Starting at 2.30?
- What about the finishing time?
- Do you want to come up with a programme for future session content?

(NB. This session did not happen, as only one co-researcher was present).

Programme for Session 20, 26th January 1999

1) Welcome back and update on progress

- Taxis – letter from Social Services Divisional Director **(hand out)** – any further action you want to take?
- Celia phoned to thank us for visiting (has everyone seen notes?)

2) Progress so far

- What the group has achieved so far **(on handout)** – how do you feel about all this?
- What else do you feel we have achieved?

3) What next?

- We need to think about what if anything you want to do next - we could:
    - have more interviews e.g. people from user forum;
    - analyse the information we got from our interviewees - what are the most important points?
    - decide what to do with this information - do you want to take any more action? e.g. write more letters, tell members' group, contact subsidised transport scheme, produce leaflet/newsletter article, etc.
    - evaluate what we've done in the group.
- (This last point is important for me - even if you decide you don't want any more meetings, I do need to talk to you to find out how you feel about this process that we've been through together, for my studies).
- We could come up with an action plan for things to do:
    - as individuals;
    - as a group;
    - with the rest of host organisation staff and members.
- You might decide that you want to keep this group going, or join in with the centre users' group and take up some of these issues via them.
- For my studies, I will need to start becoming less involved with the group from April, to stay on time, so we will need to think about how you could carry on with less involvement from me (NB. Won't disappear, but might not be able to come as often, so someone else might have to e.g. run sessions).

4) Dates for next sessions

- Do you want to carry on having weekly sessions?
- Starting at 2.30?
- What about the finishing time?
- Do you want to come up with a programme for future session content?

cont'd/...

5) Main themes

- It's a while since we had the interviews – I have done sheets with main points to refresh memories (hand out).

- What do **you** think were the most important or interesting points the interviewees made in answer to your questions?

- Are there any of these points that you want to do something about? (individually, as a group, as the host organisation).

Programme for Session 21, 2nd February 1999

1) Welcome and recap on last week's session (give out summary sheet)

- Check out with co-researchers who weren't present last week.
- Is everyone happy with this? Any other activities people want to add?
- Re. timing of sessions – reminder that I will need to start coming less as of April.
- I haven't yet had time to contact people to be interviewed – will be doing that this week.

2) Letter to Social Services (give out letter again)

- Read through with the group.
- Take point by point – see how the group want to respond.
- Any other action we want to be taking on this? e.g. writing to the subsidised transport scheme, writing to anyone else in Social Services, talking to other centre users about it? Is host organisation taking any action on this?

3) What next?

- Of the activities on the list, what else do you think you would like to do, if anything?
- How shall we go about doing that?
- I do still have a summary of information from our interviews – do you want to spend any time going back over that information?
- What shall we do in next week's session?
- Anything else you would like to talk about this week? Any other problems cropping up for you? Anything we as a group could do?

4) Conference

- In March, I've been asked to go and run a workshop at a conference in Exeter.
- It's a joint conference between researchers, health and social care professionals, and service users and carers.
- The conference is about researchers and service users working together to do research.
- I'm going to be talking about the work we've been doing in this group (not mentioning you by name or where you come from).
- The conference organisers are very keen for service users to come to the conference with researchers – if any of you would like to come to the conference with me, you're very welcome – please come and talk to me about it and I can give more details.
- If none of you want to come but are interested, I can tell you afterwards how it went and how people reacted to the work we've been doing.

Programme for Session 22, 9th February 1999

1) Update on letter

- Was it discussed at the centre users' meeting? People's views?
- I have received more information from the councillor – it makes some of the information in the social services manager's letter clearer (e.g. central day care plus outreach, community services referred to).
- I have drafted a letter to the social services manager after our discussion last week – I want to make sure you are happy with what I've put **(circulate letter)**. I will make changes and send tomorrow.

2) Transport survey

- Amy suggested doing a survey of centre users to find out who else has transport problems, to give us more evidence.
- If you still want to do that, I've come up with a draft questionnaire we could use **(circulate questionnaire)**. Views? Things to add/change?
- Do you want to do this? How? We could give out to centre users to fill in themselves, or we could sit with them and go through it?
- As we're not meeting for two weeks now, it could be something you did with them in the meantime?

3) More visitors

- Last week, agreed to invite more people to interview. So I've written to:
  - the local psychiatric hospital manager;
  - the project worker at the user forum;
  - the worker at the psychiatric hospital patients' council.
- I will wait a week for them to reply, then I will chase them.

4) Future events

- There is no session next week as there is a trip out.
- The following week is the PAG – the host organisation manager asked if people from this group would like to bring up the transport issue there again, as service funders will be present.
- We will meet again on 2nd March – hopefully we will have heard back from the people we've written to by then.
- I've also finally managed to type up the interview with the CPN and CCTL – I have copies of transcripts here if you want to read them/take them away, plus I'll do a summary sheet for the next time we meet.

- **Conference** – I've been asked to talk at a conference in Exeter in March.
- It's a joint conference between researchers, health and social care professionals, and service users and carers - about researchers and users working together.
- I'm going to be talking about the work we've been doing in this group (not mentioning you by name or where you come from).
- If any of you would like to come to the conference with me and listen to what goes on, or say something about what we've been doing, you're very welcome to come with me – please come and talk to me about it afterwards.
- If none of you want to come but are interested, I can tell you after I've been how it went and how people reacted to the work we've been doing.

Programme for Session 23, 2nd March 1999

1) Arrangements for future sessions

- We have to finish by April – there are other groups that the host organisation wants to start running, and we said from the start that it would last a year i.e. it would end March '99.
- After today, we have two more sessions – 9th March and 23rd March (there is a trip on 16th).
- So with the things that we are doing now, we have to think about how we want to carry them on in the centre e.g. via centre users' meetings, or with support from Sue.
- I'll still be around e.g. coming to centre users' meeting when relevant, but we won't be having weekly meetings like this.
- I do still want to come and talk to you all individually to see how you think this group has gone – we can set that up.

2) Update on transport

- Did it come up at the PAG? Feedback.
- I've received a letter from the social services manager **(hand out)**. It clarifies the issue about not closing the day centre.
- One of her staff will come and visit – do we want that? We could arrange it in a centre users' meeting, so that others can also be involved.
- The transport survey – it would still be useful to get information for that meeting.
- Have you had the chance to do any questionnaires? We could do some today if we have time.

3) More visitors

- Re. inviting someone from the psychiatric hospital, the only date the manager could come before our sessions end was 16th March – you're on a day trip.
- So we will have to hand that over to the host organisation – if you still want to do it, we could arrange via a centre users' meeting.
- Re. the user forum, they phoned to say that they can't do it at the moment but they might be able to come in the future, so that's something that the centre users' meeting could chase up in a few months' time.
- I haven't heard from the patients' council yet – I will get in touch with them again and pass on details to Sue.

4) Conference

- This is fully booked, so I can only take one of you with me.
- I don't know how you want to do this – if any of you are keen to come on your own with me, perhaps talk to me afterwards and I can give you more details.

5) Future sessions

- 9th – We could look at results of the transport survey if we have them.
- 23rd – Our last session, so it could be a social to celebrate what we've achieved and look at ways of keeping that going without our weekly sessions.

6) AOB

- I have the transcript here from last week if anyone is interested.

Programme for Session 24, 9th March 1999

1) Update

- We have a session today, then not next week, then it's our last session on 23rd March.
- Is there anything in particular you would like to do at that last session? I'd like to use some of it to reflect on what we've done and achieved. I will bring cakes!
- After that, I would like to come and talk to you individually if that's OK – that will be helpful for my studies.
- David is going to come with me to the conference on 26th March – he'll be able to tell you about it.
- I have the transcript from last week's session if anyone wants it.

2) Transport survey

- This week, we could do the transport survey with other centre users.
- We could go next door and ask people to fill in the questionnaires – either leave it with them, or we can talk to them and fill it in with them.

(If the group is not keen on this, go through some of the evaluation questions).

Programme for Session 25, 23rd March 1999

1) Achievements

- As this is our last session, I wanted to just spend a bit of time thinking about what we've achieved in this group (see summary sheet).
- What else do you feel we've achieved?

2) Evaluation

- It would be good to just spend a bit of time today reflecting on what you've thought about being in this group.
- Any other comments that you want to share with everyone about having been in this group together?

3) What next?

- Although the sessions are finishing, there are still things you can do if you want to:

- I've written back to Social Services about transport – I said that you might want to invite someone to come and talk to you about it at a centre users' meeting.
- We've got the transport survey results now, so you/we could send those on to the social services link officer, or invite her to come and discuss the results.
- I've written back to the manager of the psychiatric hospital, thanking her for offering to come and talk to us and saying that you might get in touch and ask her to come to a centre users' meeting.
- It came up through our letters with Social Services about the Income Maximisation Unit that they have, to make sure people are getting all their benefits. They said they would come and do a session here if people wanted that, so if you wanted that service you could ask the host organisation to arrange it for you.
- You could still use the information we've gathered to write to more people, write articles for the new host organisation newsletter, or invite more people to come and talk to you at centre users' meetings (e.g. service user groups).

- I mentioned before that I would like to talk to each of you individually about the work we've done in this group. So I will be coming back to the centre to do that with you after Easter. I'll also make sure that I still come and visit, and if you have people along to centre users' meetings I'll come along too if I'm invited!

4) Thank you!

- I just wanted to thank you all for giving your time to this group – I do appreciate it. It hasn't just been work for me – I've really enjoyed getting to know you all, and really respected how honest and open you've been with me throughout. The whole thing has been a great pleasure for me, plus working with Sue has been lovely. Many thanks to the host organisation for letting us do this.
- I hope that I will still see you – I'll have to try out host organisation lunches!

Appendix 3: Interview schedule for co-researchers

Negotiate consent re. including information and quotations from interview and discussions in thesis and other publications.

1. What has being in the group meant to you?

2. Did you get what you wanted/expected to from the group?

3. Have you benefited from the process of being in the group?
   - If yes, how?
   - If no, why do you think that is?

4. Has being in the group made any difference to your everyday life? (e.g. how you feel in yourself, how you approach other people)

5. Do you feel you have learned anything from being in the group?

6. (a) What do you feel the main purpose of the group was? e.g. research, action, talking about problems? Any other?
   (b) Has it been achieved?

7. Would you like to have done more of any of this activity in the group?

8. Do you think the group's work had any impact on:
   (a) other users of (the host organisation)?
   (b) (host organisation) staff and services?

9. Is there anything you want to say to (the host organisation) about having this sort of group?

10. Do you think the work the group has done will carry on at (the host organisation)?
    - If yes, how?
    - If no, why not?

Process issues:

1. Was there anything you did not like about being in the group?

2. What could have been done differently to make the group better for you?

3. We mostly just talked in the group. Was this the best way to run the group for you? Or could it have been done differently to make it better for you?

4. Was meeting most weeks right for you? Or would it have been better to meet less/more often?

cont'd/...

5. We met for about a year altogether. Was this long enough/too long/not long enough?

Profile information (if happy to give):

1. Age
2. Live - alone? With partner?
3. Any children?
4. Length of time using mental health system
5. On medication for mental health?
6. Perceived current state of health

Appendix 4: Interview schedule for project worker

Negotiate consent to use information and quotations from interview and discussions in an anonymised form in thesis and other publications.

A) Achievements of group

1) What did you see as being the main purpose of the group?

2) Do you think the group met people's expectations?

3) How do you feel each stage of the group process went?
   (i) talking about and sharing experiences
   (ii) finding out more about issues via sessions
   (iii) taking action based on findings of sessions

B) Individual group members

1) What do you feel each co-researcher got out of being in the group?

2) Do you feel that being in the group had an impact on their everyday lives? (e.g. perceptions of self, interactions with other people/professionals)

3) Do you feel that being in the group had any negative or unexpected effects on co-researchers?

4) Were there any particular issues or factors that you felt made it (i) easier or (ii) harder for co-researchers to participate?

C) Process issues

1) Did you feel that the process of recruiting people into the group was appropriate? Could it have been done differently?

2) Was there anything that you felt could have been done differently to help the group run more effectively?

3) How appropriate did you feel the format of the group sessions was (i.e. discussion, written documentation)? Could this have been done differently?

4) Was meeting most weeks appropriate or not? Did you feel it would have been better to meet less/more often?

5) We met for about a year altogether. Was this too long, not long enough or about right?

6) Could anything have been done differently to encourage attendance at the group, to maintain momentum?

cont'd/...

.../cont'd

D) <u>Wider impact</u>

1) What if anything do you feel you as a worker got out of being involved in the group process?

2) Do you feel the group's work had any impact on:
   (i) other users of (the host organisation)?
   (ii) other (host organisation) staff?
   (iii) other services?

3) Were there any issues for (the host organisation) in 'hosting' a project like this?

E) <u>Moving on</u>

1) Is there anything you want to say to (the host organisation)/similar organisations about having this sort of group?

2) Do you see the work the group has done carrying on?
   - If yes, how?
   - If no, why not?

Appendix 5: Topic guide for interviews with professionals

Background information

- What is your job? What does it involve?

After-care

- Why aren't there enough after-care services when you come out of hospital? Wouldn't that stop people going back into hospital?
- What sort of support is there for people coming out of hospital?
- Why are people 'dropped' by workers when they still feel 'ill'?

Community care

- Why is there such a long wait for services?
- Why aren't there enough community services?
- How do you assess needs? What criteria do you use?
- Why do some people receive a lot of services and other people not receive any?

Day care

- Why did (city centre day centre) have to close down?
- What day care services have been set up to replace (city centre day centre)?
- Will anything similar to (city centre day centre) be opening in this area?
- How do you decide what sort of day care services are provided?
- Why isn't there a day care service you can go to all day?

Voluntary services

- What voluntary services are there in this area?
- Are there any befriending schemes?
- Are there any voluntary services that would take you out on trips?
- Why aren't there any volunteer driver schemes to provide transport for service users?

cont'd/...

.../cont'd

Local psychiatric hospital

- Why aren't people given things to do at hospital? Why are they left to their own devices?
- Why do the staff at hospital stay in the office all day? Why don't they spend time with the patients?
- Why are 'really bad' patients put in with other patients at hospital?
- Why do you have to wait so late for your tablets at hospital?
- Why is it so hard to get back into hospital if you feel 'ill'?
- What services have been set up in the community to replace the ones at hospital?

Other questions

- What is the new Mental Health Trust going to be? How will it affect service users and existing services?
- Why aren't services publicised?
- Why does (the host organisation) cover the whole of (south of city) when health and social services have two teams to cover this area?

Appendix 6: Questionnaire for transport survey

1) What part of (the city) do you live in?

.....

2) How many times a week do you usually come to (drop-in centre)?

Once a week ☐
Twice a week ☐
Less than once a week ☐

3) How do you usually get to (the drop-in centre)?

By bus ☐ How many buses? .....
By taxi ☐
By (subsidised scheme) ☐
By car ☐ Who drives? .....
Walk ☐
By push bike ☐

4) How long does it take you to get to (the drop-in centre)?

.....
.....

5) How much does it cost you to get to (the drop-in centre)?

.....
.....

6) Have you ever not been able to come to (the drop-in centre) because of transport problems?

Yes ☐ No ☐

If yes, (a) please explain what these problems were:

.....
.....
.....

(b) How many times has this happened?

.....
.....

7a) Are you happy with your transport arrangements? Yes ☐ No ☐

b) What would be your ideal way of getting to and from (the drop-in centre)?

.....
.....

Appendix 7: Thematic framework and codes for data analysis (using 'Framework' approach)

Participatory research themes

Theme	Code
Phases of PR: • Phase 1: Organisation of the project and knowledge of working area	P1
• Phase 2: Problem-posing	P2
• Phase 3: Linking individual interpretations of problems to the broader social and structural context	P3
• Phase 4: Researching social reality *(including preparing to research)* and analysing collected information	P4
• Phase 5: Definition of action projects *(and carrying out action, and results of action)*	P5
• *Phase 6: Ending the research*	P6
• Group progress through PR phases	PRprog
• Evaluation/review of progress and process	eval
• Use of PR 'values' during research process	PRvalues
• Confidentiality	confidy
• Practical groupwork issues	grpwork
• Methodological issues	method

Group themes

Theme	Code
• Group attendance	attend
• Group interaction/dynamic	interact
• Commonality of experiences	comexper
• Mutual support	mutsupt
• Group consensus	grpconsens
• Co-researcher conflict/disagreement	grpconflict
• Decision-making by co-researchers	grpdecide
• Decision-making by research student/project worker	staffdecide
• Co-researcher confidence	grpconfid
• Co-researcher lack of confidence	grpnoconfid
• Group action	grpact

Subject themes (for both co-researchers' and interviewees' comments)

Theme	*Code*
• After-care/support on hospital discharge	acare
• Befriending services	befriend
• Benefits	benef
• Care planning	CPA
• Carers (informal)	carer
• Community care (CPN, community care worker, social worker)	CC
• Dependency	depend
• Day care	dcare
• Diagnosis of 'mental illness'	diag
• Discrimination	discrim
• ECT	ECT
• Funding/resources for services	fund
• GP care	GP
• Hospital closure	hospclose
• Housing	house
• Ignorance/lack of understanding of mental distress	ignor
• Information - lack of	infolack
• Inpatient mental health care	inpt
• Isolation	isol
• Leisure activities/'things to do'	leis
• Loneliness	lonely
• Medication	medicn
• 'Mental illness' - nature and effects	MI
• Needs assessment	needs
• New Mental Health Trust	MHT
• 'Out-of-hours' support	xhrssup
• Physical problems and impairments	phys
• Police involvement	police
• Professional attitudes	profatt
• Respite care	respite
• Self-help groups	shelp
• Services - lack of	servlack
• Social Services	SS
• Stigma	stig
• Support/"someone to talk to" - need for	supp
• Transport	transp
• User involvement/consultation	UI

Participant themes

Theme	Code
• Involvement/role of co-researcher A/B/C/D/E/F	roleA/B/C/D/E/F
• Co-researchers' use of 'voice' outside group	voice
• Impact of work on co-researchers	grpimpact
• Research student's role	rolestd
• Project worker's role	rolewker
• Host organisation's role	rolehost
• Interviewees' role	roleivee
• Supervisor's role	rolesup
• Fellow PhD student's role	rolepeer
• Relationship between co-researchers and research student	grp/std
• Relationship between co-researchers and project worker	grp/host
• Relationship between research student and host organisation	std/host
• Relationship between group and other host organisation users	grp/users

Conceptual themes

Theme	Code
• Power relations (e.g. between group and student/worker/interviewees)	power
• Control (of process)	control
• Empowerment	empower
• Advocacy	advoc
• Race and culture	race
• Language	lang
• Information/knowledge	info
• Gender relations	gender

Appendix 8: Handout about project used at first group session

ABOUT THIS PROJECT…

This group is somewhere where you can talk about your experiences as people who use mental health services, and learn more about the experiences of other people in the group.

This will help us all to understand more about the difficulties you face as people using mental health services living in this area.

It will be up to you what you want to talk about. There might be all sorts of things you worry about, like for example:

- **transport**
- **benefits**
- **jobs**
- **housing**
- **your medication**
- **being able to do things you enjoy**
- **getting health care and treatment you're happy with**
- **the way mental health service users are treated in hospital.**

We will also use this group to think about ways of making some of these problems better. This is the 'research' part of the project – there might be people we could talk to or send a survey to (e.g. housing workers, benefits advisers or psychiatric nurses) to find out more about why you have problems with services. I could go away and do this and then tell you what I find out, or you could come with me, just to listen or to ask questions. It will be totally up to you how much you want to get involved in this part of the project.

I hope that being in this group will give you the chance to:

- **talk about things that worry you with people that understand;**
- **say what you would like to happen to help some of these worries go away;**
- **get more information so that we as a group, (the host organisation) as an organisation or me as a researcher can let services know what you as mental health service users would like to see improve in this area.**

Ideally, the group will meet for at least 10 weeks. But this will be up to you: if we want to, we can carry on meeting together for longer.

Appendix 9: Group member attendance by session and PR phase

	Ph 1	Phases 2 & 3 of PR				Phase 4 of PR											Phase 5 of PR							Ph 6
Name	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
Rose	x	✓	✓	✓	✓*	✓*	✓*	✓*	✓	✓	x	✓*	✓*	✓	✓	x	✓	✓	x	x	✓	✓*	✓	x	✓
Amy	x	✓	✓	x	x	x	x	✓	x	✓	x	x	✓	x	x	x	✓	x	x	✓*	✓	✓	x	x	x
Sheila	✓	✓	✓	✓	✓*	✓*	✓	✓	x	x	x	✓	✓*	✓	x	x	✓	x	x	x	✓	✓	✓	✓	x
Mike	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	x	x	✓	✓	✓	✓	x	✓	x
Maria	✓	✓*	✓*	✓*	x	x	✓*	✓*	✓	✓*	✓	✓*	✓*	✓	✓*	✓	✓*	x	x	✓	x	x	x	x	x
David	x	x	x	x	x	x	x	x	x	x	x	✓	✓*	x	✓	✓	✓	x	x	✓	x	✓	✓	x	✓
Sue	✓	✓	✓	✓	✓	x	x	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	x	✓	✓
Fen	✓	✓	✓	✓	✓*	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

✓ denotes that the group member was present for the whole session.
✓* denotes that the group member was present for part of the session.
x denotes that the group member was not present at the session.

Appendix 10: Prompt questions for use at group review session

1. Have the group sessions met their expectations so far? Are they clear/happy about the purpose of the group? Does this need clarifying?

2. How have co-researchers felt about issues raised in sessions so far?

3. How comfortable have co-researchers felt? Has it been difficult to talk about issues raised?

4. Are co-researchers happy with the structure of the sessions so far? Would they like the sessions to be run in a different way (e.g. more activities/games)?

5. Are there things that co-researchers would like to cover in these sessions that haven't been covered so far?

6. Are co-researchers happy with the way information has been produced (i.e. transcript and main themes)? Would they like the information in a different format?

7. Are the co-researchers happy with Fen's role in these sessions? And Sue's? Anything they would like to change about this? Do they need more information about Fen's research?

8. What sort of timescale do the co-researchers envisage for the group? (i.e. how much longer do they want it to go on for? Do they have expectations about if/when the group might end?)

9. Do the co-researchers see this as a 'closed' group? How would they feel if other people wanted to join?

10. Any other suggestions for the way in which the group sessions might develop/could improve? Anything they want out of the group that they don't feel they're getting?

Appendix 11: Summary sheets from group sessions

"What problems have you faced as a person using mental health services?"
Main themes from group discussion, 19th May 1998

1) Loneliness and isolation

- Need for contact with other people – need someone to talk to.
- Need more to do during the day.
- Loneliness very bad in the evenings – going to bed early.

2) Closing of services

- (City centre day centre) not replaced by a daily service.
- Needs not being met.

3) Lack of understanding from GPs

- Don't have enough time for you.
- Just give you medication.
- Don't understand depression.
- Problems getting appointments and getting to see your own doctor.

4) Negative experiences at (local psychiatric hospital)

- Problems with staff – not supportive, say hurtful things.
- Feeling worse after (hospital) than before you went in.

5) Problems getting in to (local psychiatric hospital) if you feel that you need to

6) Lack of support after discharge from hospital

7) Care plan reviews not happening

- Not being told about your rights to regular care plan reviews.

8) Worries about relying on husband/partner to do everything at home

Main themes from group discussion, 26th May 1998

Are there any other services you have problems with on a day-to-day basis?

1) Transport

- If you live some distance from day care, it's hard to get there.
- Taxis are too expensive - they use up all of your mobility allowance.
- (Council subsidised transport scheme) is a good service but they can't always fit you in, or pick you up at the right time.

2) Housing

- The Council doesn't make it clear how they prioritise people for rehousing.
- It can be hard to get transferred to a bigger place - it takes a long time and you have to keep phoning them up.
- You like where you live but you get lonely.

3) Loneliness in the evenings

- Would like to have things organised in the evenings to come to.
- Not everyone knew about the (host organisation) evening drop-in on a Wednesday.

4) Need for support at home

- Don't just want medication, want someone to talk to face-to-face.
- Worries about becoming 'ill' again and what help would be available if you didn't want to go into hospital.
- Not everyone has a key worker that they see regularly.
- Experiences of being 'dropped' by keyworkers if they think you're doing all right.

Do you feel you've been discriminated against because you're a mental health service user?

1) Bad experiences at (local psychiatric hospital)

- Bad treatment by the doctors and psychiatrists - pushed around and not told what they were saying about you.
- Hurtful comments made by psychiatrists.
- No-one you felt you could complain to about this.
- No support - left on your own.
- Frightened of other people in (hospital).
- Made to go to bed when you can't sleep.
- Not flexible about when you can have your medicine.

2) Don't tell other people that you're a mental health service user

- Keep yourselves to yourselves - don't have much contact with the neighbours.
- Other people don't understand - they're frightened of you because of ignorance.

Main themes from group discussion, 2nd June 1998

Any other issues that worry you?

1) Local psychiatric hospital

- Nothing to do all day - just left sitting or told to go for a walk.
- Staff wouldn't bring your medication to your room - you had to go and get it.
- Staff shut themselves in the office and didn't spend time on the wards.
- Bad experiences in the observation ward - nothing to do and nurses sat watching you.
- Frightened of other people in (hospital).

2) The effects of depression

- It's like "going through a dark tunnel".
- You don't know how long it's going to last - can be weeks, months or years.
- Choking feelings from anxiety.
- Problems have been going on since the age of 18/19.
- ECT - helps some people but a bad experience for others.

What are the reasons why these problems with services happen?

- Health workers don't have enough time for you, just to talk.
- Health workers don't always seem interested in you.
- Some health workers don't understand depression.
- Some health workers have bad attitudes - not caring and don't respect you.
- Not enough back-up in the community to support people who are moved out of hospitals - not enough resources in the community.

Main themes from group review, 16th June 1998

- It has given people a chance to talk about things that worry them.
- Haven't been influenced by facilitators – able to talk about lots of different topics unprompted.
- Happy with how the information is produced.
- Happy with having names on the transcript as long as it remains confidential to the group.
- Fen is very good. Makes you feel confident/safe and able to talk. Easy to talk to. Seems to understand.
- Happy with Sue's role in the group.
- Feel ready to move on from previous discussions now.
- Group should continue until there is a natural ending.
- Rose and Sheila – enjoying the group.
- Mike – feels that it is better to have a closed group and wishes to continue with this.

(Present: Rose, Sheila, Mike and Sue).

Moving on - main themes from group discussion, 23rd June 1998

Now that we have talked a lot about problems experienced as mental health service users, we are moving on to think about what information we could get/who we could make contact with to try and get answers to why these problems exist.

Possible ways of doing this that we came up with were:

- passing information on to general practitioners about your views on mental health services e.g. by writing to them;

- talking to people from mental health services i.e. inviting them to attend one of these meetings to see what they have got to say.

Suggestions of people you might want to talk to included:
- community psychiatric nurses;
- social workers;
- mental health workers from (local psychiatric hospital).

Possible questions you came up with to ask them included:
- What is your job? What does it entail?
- Why are people 'dropped' by workers when they still feel 'ill'?
- Why aren't people given things to do at (local psychiatric hospital)?
- Why are 'really bad' patients put in with the other patients at (local psychiatric hospital)?
- Why do you have to wait so late for your tablets at (local psychiatric hospital)?

Information from group discussion, 30th June 1998
Questions for mental health professionals

Background information

- What is your job? What does it involve?

After-care

- Why are after-care services so poor?
- What sort of support is there for people coming out of hospital?

Local psychiatric hospital

- Why aren't people given things to do at (hospital)? Why are they left to their own devices?
- Why do the staff at (hospital) stay in the office all day? Why don't they spend time with the patients?
- Why are 'really bad' patients put in with other patients at (hospital)?
- Why do you have to wait so late for your tablets at (hospital)?
- Why is it so hard to get back into (hospital) if you feel 'ill'?

Community care

- What services have been set up in the community to replace the ones at (hospital)?
- Why are people 'dropped' by workers when they still feel 'ill'?

Day care

- Why did (city centre day centre) have to close down?
- What day care services have been set up to replace (city centre day centre)?
- Will anything similar to (city centre day centre) be opening in this area?

Information from group discussion, 7th July 1998

Interviews with mental health professionals

- We have decided to arrange interviews with mental health professionals to find out more about the issues we've been talking about in this group.

- Last week, it was suggested by some group members that:

  - we invite more than one professional to be interviewed at once i.e. we hold group interviews, with two or three professionals.
  - we invite people from (local community mental health centre) as well as other parts of (the city).
  - we hold the interview(s) at (local community mental health centre) rather than (host organisation), because the rooms are bigger.
  - we somehow give other centre users the chance to be involved in this process too.

- We also talked about the **timescale** for arranging these interviews. It was suggested that we have a break now over the summer to give Fen a chance to contact people and set up the interviews. The 'open group' will carry on as normal throughout the summer.

- We would then start meeting again at the beginning of September (suggested date Tuesday 8th September i.e. in 7 weeks' time) to prepare ourselves for the interviews with professionals, which will hopefully take place in September/October.

Things to think about

- To be prepared for these interviews, we need to think about:

  - your <u>own</u> questions to the professionals who come along.
  - <u>how many</u> group interviews you might want to hold altogether.
  - <u>how</u> you would want to involve other centre users (e.g. by actually inviting them to the group interviews? By asking them to come up with questions for you to ask? By holding a session with them after the interviews to tell them what you found out?).

Information from group discussion, 22nd September 1998
Questions for mental health professionals

Background information

- What is your job? What does it involve?

After-care

- Why aren't there enough after-care services when you come out of hospital? Wouldn't that stop people going back into hospital?
- What sort of support is there for people coming out of hospital?
- Why are people 'dropped' by workers when they still feel 'ill'?

Community care

- Why is there such a long wait for services?
- Why aren't there enough community services?
- How do you assess needs? What criteria do you use?
- Why do some people receive a lot of services and other people not receive any?

Day care

- Why did (city centre day centre) have to close down?
- What day care services have been set up to replace (city centre day centre)?
- Will anything similar to (city centre day centre) be opening in this area?
- How do you decide what sort of day care services are provided?
- Why isn't there a day care service you can go to all day?

Voluntary services

- What voluntary services are there in this area?
- Are there any befriending schemes?
- Are there any voluntary services that would take you out on trips?
- Why aren't there any volunteer driver schemes to provide transport for service users?

cont'd/...

.../cont'd

Local psychiatric hospital

- Why aren't people given things to do at hospital? Why are they left to their own devices?

- Why do the staff at the hospital stay in the office all day? Why don't they spend time with the patients?

- Why are 'really bad' patients put in with other patients at hospital?

- Why do you have to wait so late for your tablets at hospital?

- Why is it so hard to get back into hospital if you feel 'ill'?

- What services have been set up in the community to replace the ones at hospital?

Other questions

- What is the new Mental Health Trust going to be? How will it affect service users and existing services?

- Why aren't services publicised?

- Why does (host organisation) cover the whole of (south of city) when health and social services have two teams to cover this area?

Group session, 6th October 1998

Preparation for interviews

So far, we have two interviews arranged with people working in the field of mental health:

20th October	**Vicky (a community psychiatric nurse) and Sarah (a community care team leader)**
27th October	**John (Chair of Social Services Committee) and Andy (Mental Health Commissioning Manager, Health Authority)**

We need to decide:

1) TIMING OF INTERVIEWS

- Last week, it was suggested that interviews last for an hour, from 2pm to 3pm.
- We would have a break from 3 to 3.30pm, and then 3.30 to 4pm to reflect on what the interviewees have said.

2) CHAIR OF INTERVIEWS

- Who is going to chair the interviews i.e. introduce people, make sure they run on time, make sure everyone gets to say what they want to?

3) ASKING QUESTIONS

- Is everyone happy to ask questions?
- We need to try and ask people **relevant** questions.

4) RECORDING THE INTERVIEWS

- Is it OK for me to tape record interviews and then type them up?

5) INVITING OTHER MEMBERS

- Do you want to invite other centre users to these interviews, or do you want to keep it to this group?

Suggested programme for group with Fen

17th November	Interview with GP
24th November	**No session** – Project Advisory Group
1st December	**No session** – Talk from respite care provider
8th December	**No session** – Trip out
15th December	**Last session before Christmas:** - Feedback on interview with GP - What do we think about what the group has achieved so far? - Planning sessions after Christmas - Mince pies!
22nd December 29th December	**No session with Fen**

Sessions after Christmas

First meeting – 5th January

Sessions after Christmas might include:

- Interviewing people from user forum
- Analysing the information we've collected
- What shall we do with this information? Do you want to take any action?
- Evaluating what we've done in the group – group discussion and individual meetings

Feedback from GP, 10th December 1998

Celia has just phoned me at work to say thank you for all the paperwork I sent through to her after the interview, and said that:

- she had fed the key points back to the rest of her practice this morning, and they felt that the issue of advice on panic attacks should be good clinical practice. She was going to raise the issue with (emergency GP service), who do have trained doctors on early evening but not later on at night.

- she had left a message for her friend who was in a self-help group for people with a diagnosis of OCD, but had not yet heard back from them. But she said that she had had someone in her surgery this week also looking for such a group, so there was obviously a need for someone to take the initiative and set up a group like this (maybe through advertising in the newspaper?).

- she wanted to show the information in anonymised form to a friend of hers who is interested in this type of research.

She also asked whether any progress on the transport issue had been made yet.

Overall, she wanted to say thank you for inviting her along to the interview, and said that she felt very privileged to have taken part in it.

I said that I felt the group were very pleased with how the interview had gone, and appreciated the opportunity to ask a GP whatever they wanted to.

Summary sheet for group session, 26th January 1999

WHAT THE GROUP HAS ACHIEVED SO FAR

We have:

1) **talked about experiences** as mental health service users, including:
   * after-care
   * day care
   * voluntary services
   * feeling 'ill' and isolated
   * community care
   * psychiatric hospital
   * carers

2) put together a list of **research questions** on these subjects.

3) used these questions to **interview:**
   - a community psychiatric nurse
   - a community care team leader
   - a councillor
   - a health authority manager
   - a GP

4) **written letters** to the councillor to complain about problems with transport to and from day care.

WHAT NEXT?

We could:

- have more **interviews** with visitors
- look at the most important **points** from our interviews with professionals, and decide **what we want to do** with this information
- talk to the centre users' meeting about what we've been doing as a group
- do anything else you want to suggest – e.g. write more letters, make leaflets, write for a newsletter, find out more about voluntary services or self-help groups

OR we can decide not to meet any more and you can take up issues you want to in other ways – e.g. as individuals, in the centre users' meetings.

Whatever you decide, Fen would like to arrange a bit more time with each of you to talk to you about what you think of having been involved in the group. We can talk about this at our next session.

Main points from group session, 26th January 1999

We talked about what we had done in the group so far and what we wanted to do next.

Timing of sessions

We decided:

1) to have sessions every week for the next two weeks i.e. on 2nd February and 9th February. We won't meet on 16th February (trip out) or 23rd February (Project Advisory Group). On 2nd March, we will decide whether we want to carry on meeting every week or change to every two weeks.

2) to start sessions at 2.30pm, so that people can also go to the centre users' meeting. Sessions will last until 4 o'clock, with a break in the middle.

Activities at sessions

We decided:

1) to invite visitors to two more interviews: one with someone from the psychiatric hospital, and one with people from two advocacy-type groups (the local user forum and the local patients' council).

2) to write to Social Services replying to their latest letter about transport, from the Divisional Director.

Other suggestions for things to do at sessions included:

1) inviting staff from Social Services to come and talk to us in person about the transport issue.

2) writing articles (as a group and/or as individuals) for the new host organisation newsletter starting up.

3) spending a session looking for information on services and self-help groups that people are interested in getting involved with.

4) joining up with the centre users' meeting to do some activities together.

Summary sheet for group session, 23rd March 1999

Main achievements of group

We have:

1) **talked about experiences** as mental health service users, including:
   - after-care
   - day care
   - community care
   - voluntary services
   - local psychiatric hospital
   - carers
   - feeling 'ill' and isolated

2) put together a list of **research questions** on these subjects.

3) used these questions to **interview:**
   - a community psychiatric nurse
   - a community care team leader
   - a councillor
   - a health authority manager
   - a GP

4) **written letters** to a councillor and a social services senior manager to complain about problems with transport to and from day care.

5) **done a transport survey** to find out factual information about transport for all drop-in centre users.

Appendix 12: Report of results of transport survey carried out by group, March 1999

Total number of (host organisation users) who responded: 23

1) What part of (city) do you live in?

(Area 1)	1
(Area 2)	1
(Area 3)	3
(Area 4)	2
(Area 5)	2
(Area 6)	4
(Area 7)	2
(Area 8)	3
(Area 9)	4
No response	1

This shows that people come from all over (south of city) to use (the host organisation) services.

2) How many times a week do you usually come to (the host organisation drop-in centre)?

Fourteen people (61%) said that they came to (the host organisation drop-in centre) once a week. One person commented that they would come *"more if it wasn't so difficult for me to get there"*. Eight people came to (the host organisation drop-in centre) twice a week, and one person came less than once a week.

3) How do you usually get to (the host organisation drop-in centre)?

(NB. Three people gave more than one answer to this question)

By bus	10 people
By taxi	5 people
By (subsidised scheme)	4 people
By car	4 people
Walk	3 people

This shows that people coming to (the host organisation drop-in centre) use a range of different means of transport, including public transport, subsidised transport (council scheme), private taxis and lifts from family members.

4) How long does it take you to get to (the host organisation drop-in centre)?

5-10 minutes	8 people (by car/taxi/subsidised scheme)
15-20 minutes	7 (by taxi/subsidised scheme/bus/walking)
25-30 minutes	4 (by taxi/bus/walking)
One hour	6 (by bus)

cont'd/...

While people travelling to (the host organisation drop-in centre) by car, taxi or (the council-subsidised transport scheme) have relatively short journey times, the majority of people using the bus reported having to travel for an hour to get to (the host organisation drop-in centre). This challenges the idea of this being a local and accessible service for people across (the south of the city).

5) **How much does it cost you to get to (the host organisation drop-in centre) and back?**

£1-£1.90	11 people (by bus, subsidised scheme, and car)
£2-£2.60	4 (by bus and subsidised scheme)
£4	1 (by taxi)
£7	2 (by taxi)
£8	1 (by taxi)
£15	1 (by taxi)
Cost of petrol	2 (by car)
Nothing	1 (walk)

This shows that buses and (the council-subsidised transport scheme) are the cheapest ways for people to get to (the host organisation drop-in centre). The cost of a taxi, at between £4 and £15 a day, is clearly likely to be beyond the means of many people living on limited incomes.

6) **Have you ever not been able to come to (the host organisation drop-in centre) because of transport problems?**

Yes	12 people (52%)
No	11 people (48%)

So over half of (the host organisation drop-in centre) users surveyed reported having been unable to come to (the host organisation drop-in centre) because of problems with transport.

People were asked to explain what transport problems they had experienced. Six people mentioned problems with (the council-subsidised transport scheme), and all said that these problems had happened several times:

"...(Subsidised scheme) wrong area not always able to book on right day booking office seems unsure about boundaries etc."

"(Subsidised scheme) unable to fit me in."

"Phoned (subsidised scheme) but they were rude and very unhelpful. Put me off ringing again."

"(Subsidised scheme) unable to take me, and these days I feel I cannot go on bus."

cont'd/...

Two people mentioned financial problems preventing them from accessing transport to come to (the host organisation drop-in centre):

> *"Money problems. Long way from (one southern part of city). Not surviving on income support."*

Two more people, both bus users, stated that they had physical difficulties which made it more difficult for them to get to (the host organisation drop-in centre):

> *"Hill too steep to walk up with asthma."*
>
> *"Problems with epilepsy."*

One person stated that they had problems as the bus routes were not convenient, another said that their taxi had failed to arrive several times, and a third person felt that it was sometimes too far to walk to (the host organisation drop-in centre) in bad weather.

The main areas of difficulty with transport therefore seem to have been with (the council-subsidised scheme): people have experienced problems with (the subsidised scheme) fitting them in, and also with (the subsidised scheme) stating that they did not come within their geographical area. Physical difficulties also make transport more of a problem for some people, particularly those attempting to travel by bus and then having to walk from bus stops to (the host organisation drop-in centre). Financial concerns also stop people from accessing transport to come to (the host organisation drop-in centre) sometimes.

7) Are you happy with your transport arrangements?

Yes	7 people (30%)
No	14 people (61%)
No response	2 people (9%)

Over 60% of people responding to the survey stated that they were unhappy with their transport arrangements for travelling to (the host organisation drop-in centre).

When asked what would be their ideal way of getting to and from (the host organisation drop-in centre), seven people said that they would like to be able to travel by taxi or car. Four people wanted a more effective (council-subsidised) scheme. One person suggested a volunteer car scheme.

People's comments included:

> *"Getting bus fares back."*
>
> *"By minibus! from door to door."*

cont'd/...

"Free transport."

"More availability on (subsidised scheme) or similar transport."

"(Subsidised scheme) when it works. Taxis cost £6 each way."

"Regular (subsidised scheme) would be ideal, as this don't seem to be working. Shared taxi would be another way."

"Paid taxis or (subsidised scheme) if they can bring me every day I want to come."

"I would be more happy if it was easy to get to (the host organisation drop-in centre) as I can't use public transport i.e. if (the host organisation drop-in centre) had own transport even if we had to pay a small charge to use the service."

These comments all show how important financial considerations are to these service users, many of whom are on limited incomes.

It seems that ideally people would like some type of taxi or car service, but this would need to be a free or subsidised service in order for people to be able to attend as often as they would like to.

Appendix 13: Host organisation proposal to Social Services Department for subsidised taxi scheme

SERVICE USER TRANSPORT SCHEME

SERVICE COSTS

4 taxis plus drivers		
Tuesdays £36 x 52 weeks	=	£1,872.00
Wednesdays £36 x 52 weeks	=	£1,872.00
Sub-total	=	£3,744.00

ADMINISTRATION COSTS

10% of overall grant	=	£374.00
TOTAL	=	£4,180.00

Host organisation management costs ?

Estimated maximum income
£2 x 8 passengers x 52 weeks = £1,664.00

Appendix 14: Further information provided by host organisation to Social Services Department on proposed subsidised taxi scheme

Further information

There are currently 8 people using (the host organisation drop-in centre) groups who would be eligible to use a transport service. However this number may fluctuate during a twelve-month period, depending on the health of current service users and the needs of new referrals.

We are proposing to contract (name of taxi firm) to provide four taxis and drivers to pick up service users across the (south of the city) area, for the Tuesday and Wednesday services held at (the host organisation drop-in centre). (Name of taxi firm) have agreed to hold a list of members eligible to use the scheme, and members would be able to book their transport directly through (name of taxi firm).

We have been quoted:

Tuesday – 6 people x 2 taxis = £36.00

Wednesday – 8 people x 2 taxis = £36.00

To be paid monthly by invoice.

Members would be asked to make a contribution of £2.00 for a return journey.

It would be helpful to start the service as soon as possible so that a six-month service can be evaluated in April 2000. If successful next year's scheme would run from 1st April 2000 until 31st March 2001.

Concerns

There is a fundamental problem of any transport scheme and this is that there needs to be someone who is able to co-ordinate and review the service. Unfortunately the staff team at (the host organisation drop-in centre) is small and resources are limited. Therefore there needs to be some sort of negotiation between Social Services and (the host organisation) about the implementation of any transport service, especially as this is a pilot scheme.